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The Normative Approach of the Catholic Tradition in the Ethical and Religious Directives for Resolving Ethical Dilemmas Regarding Medical Technology

David G. Garvis

THE NORMATIVE APPROACH OF THE CATHOLIC TRADITION IN THE ETHICAL AND RELIGIOUS DIRECTIVES FOR RESOLVING ETHICAL DILEMMAS REGARDING MEDICAL TECHNOLOGY

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Deacon David Garvis

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Gerard Magill, PhD The Vernon F. Gallagher Chair Integration of Science, Theology Philosophy and Law Professor of Healthcare Ethics (Dissertation Director)	Henk ten Have, MD, PhD Director, Center for Healthcare Ethics Professor of Healthcare Ethics (Committee Member)
Joris Gielen, PhD Asst. Professor, Center for Healthcare Ethics (Committee Member)	Henk ten Have, MD, PhD Center for Healthcare Ethics (Director)
James Swindal, PhD Dean, McAnulty College and Graduate School of Liberal Arts	

ABSTRACT

THE NORMATIVE APPROACH OF THE CATHOLIC TRADITION IN THE ETHICAL AND RELIGIOUS DIRECTIVES FOR RESOLVING ETHICAL DILEMMAS REGARDING MEDICAL TECHNOLOGY

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The dissertation engages the Catholic Tradition enunciated in the *Ethical and Religious Directives for Catholic Health Care Services* to provide a normative approach for resolving ethical dilemmas regarding pivotal breakthroughs in medical technology.

This normative ethical approach has two components: a normative framework for Catholic health care ethics that adopts practical ethical principles as enunciated in the Ethical and Religious Directives (Chapter 2) and secular decision-making models in organizational and clinical ethics that are consistent with the Catholic Tradition (Chapter 3).

At the end of the theoretical analysis in these chapters, the conclusion to Chapter 3 explains how this normative approach reflects the Catholic Tradition on Natural Law. This normative approach is then applied to significant ethical dilemmas regarding a

variety of pivotal issues that deal with medical technology: reproductive technologies (Chapter 4), regenerative technologies (Chapter 5), and end-of-life technologies (Chapter 6). The conclusion of each of these practical chapters applies the Natural law approach of the Catholic Tradition to offer an ethical critique of each topic based on the Ethical and Religious Directives.

DEDICATION

To my lovely wife, Janice, my best friend who has cajoled, encouraged, and masterfully guided me along this journey.

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To Almighty and Gracious God, whose hand through the Spirit, has guided me with patience, wisdom, and endurance.

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Chapter 1. Introduction: Technological Imperative in Health Care.

The thesis of the dissertation is that the Catholic Tradition enunciated in the *Ethical and Religious Directives for Catholic Health Care Services* provides a normative approach for resolving ethical dilemmas regarding pivotal breakthroughs in medical technology.

The dissertation analyses the normative approach of the Catholic Tradition for resolving *ethical* dilemmas regarding medical technology. Specifically, the normative approach focuses upon the *Ethical and Religious Directives for Catholic Health Care Services,* published by the United States Bishops (5th edition, 2009). The normative ethical approach has two components: a normative framework for Catholic health care ethics that adopts practical ethical principles as enunciated in the Ethical and Religious Directives (Chapter 2); and secular decision-making models in organizational and clinical ethics that are consistent the Catholic Tradition (Chapter 3).

This normative approach in the *Ethical and Religious Directives for Catholic Health Care Services* is then applied to resolve significant ethical dilemmas regarding a variety of pivotal issues that deal with medical technology. Chapter 4 applies the normative approach to discuss reproductive technologies that deal with the status of the human embryo regarding personhood, stem cells, in vitro fertilization, prenatal testing, and newborn screening. Chapter 5 applies the normative approach to discuss regenerative technologies that deal with genetic enhancement, germline genetic modification, mitochondrial DNA interventions, and gene editing using clustered-interspaced short palindromic repeats protocol (CRISPR). Chapter 6 applies the normative approach to discuss end-of-life technologies that deal with changing attitudes to death and dying, the

debate over medical futility, and the controversies around the withdrawal of life-sustaining treatment.

The concluding chapter summarizes the analysis to highlight the contribution of the Ethical and Religious Directives as a normative approach for resolving ethical dilemmas regarding pivotal breakthroughs in medical technology.

With the rapid advancement in medical technology, significant ethical dilemmas emerge that challenge the established norms. Due to accelerated medical technology advancements, ethics is pressured to keep pace.

The distinctive contribution of the dissertation is to analyze the normative approach of the Catholic Tradition for resolving ethical dilemmas regarding medical technology.

The significance of this dissertation is to engage the ever-accelerating pace of new medical technology and its impact on patient care; there is a need for normative guidance that the Ethical and Religious Directives offer to those in Catholic health care, recognizing that the analysis also could be helpful for non-Catholic health care. The outcome is to provide normative guidance offered by the Ethical and Religious Directives that can systematically be applied to new technology.

Chapter 2. Normative Framework of Catholic Health Care Ethics.

I. *The Ethical and Religious Directives for Catholic Health Care Services.*

The normative framework of Catholic health care ethics is presented in the Ethical and Religious Directives. The Ethical and Religious Directives are a body of moral principles that introduce Catholic Church teaching on ethical standards for behavior to provide authoritative and normative guidance on moral issues in health care. The Ethical

and Religious Directives are grounded on three leading concepts: social responsibility, pastoral responsibility, and professional responsibility.

A. Social Responsibility.

The first foundational concept in the *Ethical and Religious Directives for Catholic Health Care Services* is that of social responsibility. Here, the Ethical and Religious Directives present a biblical foundation that is integrated with moral responsibility in health care.[1] On the one hand, regarding the issue of the biblical foundation with moral responsibility, recognition of and attention to the spiritual dimensions and spiritual struggles of patients are imperative to those charged with their care. With regard to spiritual dimensions, a community of healing and compassion incorporates not only the treatment of the malady but encompasses the psychosocial and the spiritual dimension of the human person.[2] Without health of the spirit, little hope for healing the whole person can be achieved through focused technology alone.[3] The spiritual dimension, "the search for the sacred" or spirituality, must be nurtured for us to become communities of healing and compassion. With regard to spiritual struggles, they may emerge in this quest for the sacred when patients are very sick.[4] Stressful life events can throw a pall over the view that God is a loving, all-powerful being who seeks only good things for us.[5]

B. Pastoral Responsibility.

On the other hand, to expand on the concept of pastoral responsibility, the concept of pastoral care accompanies that of spiritual responsibility. The concept of pastoral care involves two related features: to minister and to shepherd the patient. With regard to ministering to patients, we must maintain an attitude of protectiveness and solicitude.[6]

With regard to shepherding, empathy, genuineness, humility, and hope, tempered with realism are essential. Hope can foster healing.[7]

C. Professional Responsibility.

In addition to foundational concepts of social and pastoral responsibility, the Ethical and Religious Directives also address the basic concept of professional responsibility. In the concept of professional responsibility that addresses the patient-physician relationship, three areas stand out: informed consent, surrogate decision-making, and the need for a conscience clause that protects physicians. Each is considered briefly.

On the one hand, regarding informed consent, there are two constituent parts: the purpose and the components of consent. With regard to the purpose of informed consent, it is to provide a safeguard for a patient's dignity and autonomy.[8] With regard to the standard components of informed consent, they are competency, disclosure, understanding, and voluntariness.[9] To accomplish an effective process, five more specific elements are needed for informed consent: (1) the diagnosis, (2) the treatment plan, (3) the risk and benefits of treatment, (4) any alternative treatments, and (5) the risk and benefits of declining treatment.[10]

On the other hand, the topic of professional responsibility addresses the role of surrogate decision-making. With regard to the function of the surrogate, it is to serve as the patient's representative making health care decisions based upon substituted judgment for patients who no longer have decisional capacity.[11] With regard to naming and advising surrogate decision-makers are critical in making the patient's wishes known.[12]

Furthermore, professional responsibility typically involves the need for a conscience clause to protect clinicians. Three topics shed light on the conscience clause: the historical perspective, consent paradigms, and physician perspectives. With regard to the historical perspective, with the advent of secularism and the effect of patient autonomy, a need arose for the protection of physicians.[13] With regard to consent paradigms, they exist to critique the just distribution of medical services.[14] With regard to the physician's perspective about the patient, a variety of topics arise for discussions, such as physician refusal, disclosure, discrimination, and abuse of power.[15]

II. Practical Ethical Principles for Catholic Health Care.

The above basic concepts of social, pastoral, and professional responsibility led the *Ethical and Religious Directives for Catholic Health Care Services* to develop practical ethical principles for Catholic health care. These principles are based on the premise that man is not the master of his life; God is and has dominion over it.[16] The practical ethical principles in the Ethical and Religious Directives address the following: the distinction between ordinary and extraordinary means of treatment, the principle of double effect, and the principle of cooperation. These are discussed in turn.

A. Ordinary and Extraordinary Means.

First, the focus on practical principles in the Ethical and Religious Directives deals with the distinction between ordinary and extraordinary means. On the one hand, historically two perspectives emerged, the pivotal distinction made by early theologians and concerns over subjectivism and vitalism. With regard to early theologians, a stance emerged that is explained in the Ethical and Religious Directives in this way, "A person has a moral obligation to use ordinary or proportionate means to preserve his or her

life."[17] The distinction between ordinary and extraordinary means can be traced back to St. Thomas Aquinas (1274 d.). With regard to concerns arose over subjectivism and vitalism these points are pivotal. Subjectivism tends to focus only on the self, ignoring other relevant aspects of proper patient treatment. And the concern over the concept of vitalism is that it can seek to maintain life at all cost, again ignoring other relevant aspects of proper patient treatment.[18]

On the other hand, the distinction between ordinary and extraordinary means sheds light on decision-making foundations. Two points need to be addressed here: defining elements and moral assessment. With regard to ordinary means, there are four major defining elements for making distinctions: (1) reasonable hope of benefit, (2) common means, (3) proportionate according to status, and (4) undemanding means.[19] On the other hand, there are four aspects in helping to determine extraordinary means: (1) great effort, (2) enormous pain, (3) significant expense, and (4) severe dread.[20] With regard to moral assessment, each case must be considered on its own merits. The criteria for decision-making need to relate primarily to the patient, not the remedy.[21]

B. The Principle of Double Effect.

The second focus of practical principles in the Ethical and Religious Directives deals with the principle of double effect. Here the distinction between ordinary and extraordinary means is applied to provide practical distinctions to resolve moral dilemmas. To discuss the principle of double effect, it is helpful to look at its historical perspective before considering its implementation.

On the one hand, the historical perspective of the principle of double effect has two related aspects, the formulation of the principle and the debate-shaping standard.

With regard to the formation of the principle, St. Thomas Aquinas (1274 d.) was the first to formulate the principle. Aquinas was the first to explicitly develop the principle regarding self-defense where there are two effects, one good and one bad. With regard to the debate-shaping standard, in developing the principle, the concepts of dual effects, intentions, and proportionality were adopted.

On the other hand, in the implementation of the principle of double effect, two aspects are highlighted: the conditions and application. With regard to the conditions, there are four that must be satisfied:

1. The action and its effects must not be morally evil.
2. The good effect must not be caused by the bad effect.
3. There must be no intention of the bad effect.
4. The good effect must outweigh the bad effect.

If an action meets all four conditions, then it is considered legitimate and acceptable.[22]

With regard to the application of the principle of double effect, it was adopted to distinguish between killing and allowing to die. The principle of double effect is one of the most useful normative tools of Catholic moral theology in general and health care ethics in particular.[23]

C. Principle of Cooperation and Complicity.

The third focus of practical principles in the Ethical and Religious Directives deals with the principle of cooperation to address issues of complicity. The principle of cooperation was developed to analyze a person's moral action and to help determine whether one's action contributes to the wrongdoing of another.[24]

On the one hand, from a historical perspective, the purpose and theological development of the principle are pivotal. With regard to the purpose of the principle, it was originally formulated with the goal of helping confessors clarify how to act morally when individuals came in contact with the actions of others involved in wrongdoings. With regard to theological development, St. Thomas Aquinas (1274 d.) was one of the first theologians to give direction for the principle. The principle can be seen as an application of the principle of double effect. Cooperation involves two agents with distinct moral actions while the principle of double effect involves a single moral agent with good and bad effects related to the action.[25]

On the other hand, the historical development of the principle has led to these two basic distinctions: formal and material cooperation. With regard to formal cooperation, it addresses actions that are wrong in all circumstances and distinguishes the action of a person cooperating. Intentionality is critical in assessing formal cooperation.[26] With regard to material cooperation, in some way, one is involved with the wrongdoer but does not share in the intentionality of the wrongdoing. Prudence must guide those involved in regards to questions of intention, duress, distance, and gravity.[27]

The practical ethical principles of Catholic health care including ordinary and extraordinary means, double effect, cooperation, and complicity have given us basic principles to better implement the Ethical and Religious Directives. All of this provides a normative framework for Catholic health care ethics, thus providing a foundation for the ethical decision-making models to be dealt with in the following chapter.

III. Conclusion.

The final section of the chapter presents a critique of the ethical analysis from the normative perspective of the *Ethical and Religious Directives for Catholic Health Care Services.*

Chapter 3. Ethical Decision-Making Models Consistent with Catholic Ethics.

To discuss ethical decision-making models consistent with Catholic ethics requires examining three related topics: moral agency and organizational ethics, the competence of patients for making end-of-life decisions, and the role of clinical ethics consultation services.

I. Organizational Ethics and Moral Agency.

Moral agency in organizations means that organizations, as well as individuals within them, are accountable for making right or wrong decisions. Both the organization as an institution and its employees must be morally responsible for the performance of assigned duties.[28] The significance of moral agency here can be understood by examining its characteristics and their connection with moral theories.

A. Characteristics.

First, the characteristics of organizational moral agency engage two foundational issues: the purpose of moral agency and the role of ethics in the organization.

On the one hand, organizational moral agency highlights ethical aims and accountability. With regard to ethical aims, they are manifested as organizational goals related to mission statements, strategic plans, and budgets.[29] With regard to ethical accountability, this involves creating an 'ethical climate' and evaluating whether actions fit within that climate.[30]

On the other hand, the role of ethics in the health care organization engages clinical and organizational ethics. With regard to clinical ethics, there are organizational ramifications.[31] With regard to organizational ethics, the health care organization can negatively impact the clinical environment by not giving appropriate ethical considerations to organizational as well as clinical decisions.[32]

B. Ethical Theories and the Ethical Climate in Health Care Organizations.

Second, in addition to the above characteristics, ethical theories impact the health care organization in two ways: relating business ethics with the ethical climate of the organization.

On the one hand, business ethics raises issues about stakeholder theory and professional ethics. With regard to stakeholder theory, it is defined as a framework for discerning conflicts of value, loyalty, commitment, and interest of the affected group of individuals.[33] With regard to professional ethics, there can be conflict among the organization's various interests.[34]

On the other hand, fostering an ethical climate in the organization is indispensable, requiring a focus on managed care organizations and organizational ethics programs. With regard to health maintenance organizations, they are designed to slow health care costs while simultaneously providing enhanced health care to a defined group.[35] With regard to organizational ethics programs, they have emerged because of the prodding and insistence of the Justice Department and Organizations that deal with health care standards, i.e. The Joint Commission.

II. Clinical Ethics and Competency.

The challenges mentioned above of organizational ethics and moral agency has often led to the compromise of patient's rights. The Catholic Church asserts patients have a right to make their health care decisions.[36] "The decision should be made by the patient if he is competent and able or, if not, by those legally entitled to act for the patient, whose reasonable will and legitimate interest must always be respected."[37] To discuss clinical ethics and competency consists of examining two related topics: competency of the patient and advanced directives.

A. Competency.

First, the fundamental concept in bringing decision-making of the patient to fruition is that of determining competency. Competency engages two foundational issues: decisions by competent patients and decisions for incompetent patients.

On the one hand, the competencies of patients are highlighted by paternalism and treatment decisions. With regard to paternalism, it is when another decides on behalf of the patient; as a result, the patient's autonomy is limited.[38] With regard to treatment decisions, when they are contextual, only the patient knows what is most important.[39]

On the other hand, another challenging aspect of competency is dealing with incompetent patients. With regard to determining capacity, it is one of the most vexing and crucial problems for physicians; performance of capacity assessment is the only means to offer protection to both patient and physician.[40] Assessing decision-making capacity falls into four categories: ability to articulate a choice, capacity to understand information, ability to appreciate consequences, and capacity to manage information.[41] With regard to guidance standards, once incapacity has been determined, three clear

guidance standards apply to decision-making: substituted judgment, substituted judgment combined with best interests, and best interest offering guidance to the surrogate and the health care providers.[42]

B. Advance Directives.

Second, these competency-determining challenges reveal the crucial need for advance directives. The advance directives are impacted in two ways: advance care planning and end-of-life care planning.

On the one hand, advance care planning raises issues about both a definitive process and clear communication. With regard to the process, patients must explore, discuss, articulate, and then document their preferences for medical treatment reflecting their values and goals. With regard to clear communication, once values and goals are determined, clear communication of these must be made to appropriate stakeholders.[43]

On the other hand, care planning at the end-of-life involves choosing a surrogate and the Patient Self-Determination Act. With regard to selecting a surrogate decision-maker, it is a critical decision.[44] With regard to the Patient Self-Determination Act (1990), it is a federal statute passed to ensure patient preferences guide medical care in the event of their incapacity assuring the desired medical care the patient wishes.[45]

III. Clinical Ethics Consultation.

An inherent relationship exists between clinical and organizational ethics. Thus an ethics infrastructure is an essential component of an organization's ethics integration and strategy. The ethics infrastructure links fundamental processes in clinical practice to the mission and core values of the organization. To accomplish effective clinical ethics

consultations require examining three related topics: the ethics approach, the quality and professionalism, and case analysis.

A. Ethics Approaches.

First, the focus of ethics approaches engages two foundational issues: ethics consultation system and the Veterans Health Administration.

On the one hand, the ethics consultation system highlights ethical dilemma analysis and various models. With regard to ethical dilemmas they can be analyzed using the following four topics: (1) medical indications, (2) patient preferences, (3) quality of life, and (4) contextual features.[46] With regard to models, three distinct models exist to accomplish ethics consultations: an individual consultant, an entire ethics committee, and the ethics consultation team.[47]

On the other hand, the Veterans Health Administration System has two models, the IntegratedEthics model, and the CASES approach. With regard to the IntegratedEthics model, it is an innovative and comprehensive design impacting multiple areas of health care by changing the focus of ethics from a reactive, case-based encounter to one that adopts a proactive and comprehensive model.[48] With regard to the CASES approach, it is the Veterans Health Administration system's five-step approach to ethical consultation: (1) clarify, (2) assemble, (3) synthesize, (4) explain, and (5) support.[49]

B. Quality and Professionalism.

Second, accomplishing quality and professionalism is a key to success of the ethics consultation. To that end, process standards and certification and attestation are two fundamental elements in achieving quality and professionalism.

On the one hand, process standards raise issues about goals of the health care ethics committee and knowledge and evaluation areas. With regard to the health care ethics committee, quality and professionalism in health care are overreaching goals of the health care ethics committee.[50] With regard to knowledge and evaluation areas, the American Society of Bioethics and Humanities has established six areas necessary for operating a successful health care ethics service.[51]

On the other hand, to achieve professionalism in the health care ethics, certification and attestation are comprised of certification requirements and the evaluation process. With regard to the certification requirements, they would entail a formal training program and supervised apprenticeship.[52] With regard to the evaluation process, a collection of written work and an oral exam would demonstrate the consultant's skills, experience, and ability to express ideas; this is the model currently being implemented.[53]

C. Case Analysis.

Third, a final integral part of an ethics consultation is the creation of a patient case analysis. For clinical ethics and case analysis to be useful, one must start with as clear a perspective as possible. Integral to case analysis are constituents features and value judgments.

On the one hand, constituent features raise issues about medical indicators and patient preferences. With regard to medical indicators, they help properly document the patient's condition to facilitate the appropriate treatment.[54] With regard to patient preferences, the fundamental principle of all morality is respect for persons and that every person has value and dignity.

On the other hand, an additional area in an effective case analysis is determining the value judgments of the patient. Comprising value judgments are quality of life and contextual features. With regard to quality of life, it is an aspect of determining patient satisfaction.[55] While satisfaction is a value judgment, it is important to provide empirical basis using such measures as mobility, daily living activities, pain, social interaction, and mental acuity.[56] With regard to contextual features, they are prerequisites for a successful case analysis. Contextual features include proximal factors such as family, financial, security, education, employment, leisure, and social support. The elements included are a community, culture, economics, healthcare system, historical, social factors, media, geography, and the ecosystem.[57]

IV. Conclusion of Chapters 2 and 3: Critique Based on the Ethical and Religious Directives.

Discussed here are the *Ethical and Religious Directives for Catholic Health Care Services* whereby Catholic teaching is applied to dilemmas in health care. This involves an alignment of the two main approaches of Natural Law, the nature-oriented and the person-oriented approaches. The final section of the chapter presents a critique of the ethical analysis from the normative perspective of the Ethical and Religious Directives.

Chapter 4. Reproductive Technology.

Reproductive technology raises fundamental questions about the normative framework of propagation. To adequately discuss reproductive technology requires examining four related topics: embryo and personhood, stem cell technologies, prenatal testing, and newborn screening.

I. Embryo and Personhood.

The relation between embryo and personhood integrates prenatal status, and personhood, with an accompanying ethical framework.

A. Embryo: Prenatal Status.

First, a consideration of the prenatal status of the embryo engages two foundational issues: the meaning of essence and the problem of dualism.

On the one hand, the meaning of the essence of the prenatal embryo highlights debates on essentialism and personhood. With regard to essentialism, humans are deemed to be persons who could not exist without being a person at the time of being an embryo.[58] With regard to personhood, the embryo has qualities that give rise to its moral worth. The core biological similarity is the first argument for moral equivalency; each embryo has a human genome.[59]

On the other hand, the debate on dualism connects dualism with animalism each focusing on what exists. With regard to dualism, it has a variety of forms, including ontological and metaphysical, soul-body, mind-body, constitutionalism, and moral.[60] With regard to animalism, it highlights the biological life of the vast majority of individual humans (except twinning) because human DNA is established at conception.[61] Animalism highlights the biological life of human nature; thus humans, the argument claims, are entitled to moral respect.[62]

B. Personhood.

Second, the debate on personhood revolves around two opposing views, the secular and religious.

On the one hand, the secular view raises issues about fertilization and potentiality. With regard to fertilization, when it occurs a unique genotype is established that determines the organization and development of the embryo.[63] With regard to potentiality, proponents of this view contend that the zygote is not yet an individual but does have the potential to become one.[64]

On the other hand, the religious view focuses on the Catholic Tradition and contemporary religious traditions. With regard to the Catholic Tradition, varying views of the status of the embryo and fetus existed.[65] With regard to other contemporary religious traditions, they have varying views of the moral significance of the early embryo.[66]

C. Ethical Framework.

Third, an ethical framework has developed around the above discussions on the prenatal status and human personhood. This framework revolves around theological-based frameworks and discussion on spirituality and humanity.

On the one hand, theologically based frameworks raise questions about embryo protection and respect for wholeness. With regard to embryo protection, the bioethical principle of non-malfeasance frames the debate.[67] With regard to respect for wholeness, the argument is driven by the potential for medical benefits and a vision of what humanity could become.[68]

On the other hand, discussions on spirituality and humanity engage two normative aspects about the spiritual soul and human dignity. With regard to the spiritual soul, it refers to the innermost essence of an individual in relationship with God. The soul is the seat of both self and moral agency.[69] With regard to human dignity, it refers to the inherent value that cannot be reduced to one's instrumental worth.[70]

II. Stem Cell Technologies and In Vitro Fertilization.

The previous section on the personal or "ensouled" status of the human embryo raises significant ethical issues for human embryonic stem cells and in vitro fertilization. The most intense debates engage three related topics: the relevance of personhood, the resourcing stem cells, and in vitro fertilization used for embryo health.

A. Relevance of Personhood.

First, the relevance of personhood in the debate on stem cell technology engages two foundational issues: the secular view and the Catholic view.

On the one hand, the secular view highlights discord in definitions and the contribution of a utilitarian view. With regard to the discord in definitions, an agreed stance on personhood has not been achieved.[71] With regard to the utilitarian view, the focus tends to be more on when an individual can contribute to social life.[72]

On the other hand, the Catholic view of personhood considers the beginning of life and the protection of life. With regard to beginning of life, the above discussion has indicated that semantic issues, biological issues, philosophical and theological issues have to be taken into account when answering the question: When does life begin?[73] In Catholic teaching, ensouled human life begins at the moment of conception thus must be respected and protected. In this tradition, every innocent being has an inalienable right to life. With regard to the protection of life, because a fertilized egg (zygote) is a human person, a moral obligation exists to protect that person.[74]

B. Resourcing Stem Cells.

Second, the debate on personhood clarifies when stem cell can be resourced. In the debate on resourcing stem cells, two primary sources should be considered: embryonic and adult stem cells.

On the one hand, embryonic stem cells highlight the debate on moral status with accompanying ethical dilemmas. With regard to the moral status of stem cells, it revolves around the ethical debate on the beginning of human life and its moral value.[75] With regard to accompanying ethical dilemmas, embryonic stem cell research, even if it involves the destruction of embryos, offers potential benefits of new medical treatments. The argument contends that a moral middle ground is needed.[76]

On the other hand, adult stem cells have two unique characteristics that need to be considered in the ethical debate: telomeres and the differentiation potential. With regard to telomeres, they are protective coverings at the end of chromosomes that keep them from unraveling. Efforts are now underway to reverse adult stem cells to their original state called 'induced pluripotency,' which could eliminate the need for the utilization of highly contentious embryonic stem cells.[77] With regard to differentiation potential, stem cells are cells that self-renew and can also give several differentiated cell types such as muscle, heart, and brain cells.[78]

C. In Vitro Fertilization and Embryo Health.

Third, the connection between the personhood debate and resourcing stem cells raises significant implications for the use of in vitro fertilization for embryo health. Hence, it is necessary to engage each point separately: in vitro fertilization and embryo health.

On the one hand, in vitro fertilization needs to be understood ethically from a historical view and a Catholic view. With regard to a historical view, prior to 1978 infertile women were without an option other than adoption. The success of in vitro fertilization has unleashed a barrage of social, ethical, and legal concerns.[79] With regard to Catholic teaching that prohibits in vitro fertilization, the Church states that a child has a right to be conceived in the marital embrace of its parents. Human intercourse has two components, unitive and procreative. In vitro fertilization separates these components, thus the Catholic Church forbids it.[80]

On the other hand, in vitro fertilization can be used to foster embryo health (rather than for fertility purposes as discussed above). When in vitro fertilization is adopted for the health of the embryo, it engages two issues, the regulation of in vitro fertilization and the development of the Catholic view. With regard to regulations, significant progress has been achieved in the promotion of quality management, risk management, and safety.[81] With regard to the development of Catholic Church's view, it is feasible that using this technology to foster the life of the embryo or to use unwanted and frozen in vitro fertilization embryos for research might be acceptable.[82]

III. Prenatal Testing.

The above discussion on the personal status of the embryo and its relevance for stem cell technology connects with the ethical debate on prenatal testing as a crucial aspect of the ethics of reproductive technology. To discuss prenatal testing requires examining two related topics: the availability of testing and interventions and what may be in store for tomorrow's children.

A. Availability of Testing and Interventions.

First, the availability of testing and interventions raises two issues: options for prenatal testing and prenatal genetic interventions.

On the one hand, prenatal testing deals with issues related to non-invasive prenatal testing and expanded carrier screening. With regard to non-invasive prenatal testing, the American College of Obstetrics and Gynecology concluded that this testing should be offered to patients who may be high risk for fetal aneuploidy (abnormal number of chromosomes).[83] With regard to expanded carrier screening, which contributes to next-generation sequencing, it is shifting from ancestry based to one that screens for disorders to decrease inherited genetic diseases.[84]

On the other hand, prenatal genetic interventions deal with the prenatal genetic diagnosis, prenatal genetic therapy, and prenatal genetic enhancement. With regard to prenatal genetic diagnosis, which has been used for adverse selection and targeting genetic diseases, ethical dilemmas need to be considered including: devaluing the disabled and discrimination of people with disabilities.[85] With regard to prenatal genetic therapy, there are three types: therapy on the gametes before fertilization, therapy on embryos before implantation, and therapy on fetuses by injecting genetic material. Each can be problematic.[86] With regard to prenatal genetic enhancement, a primary concern is the best interests of the child-to-be as well as the effects on society.[87]

B. Tomorrow's Children.

Second, the availability of prenatal testing has significant implications for tomorrow's children. Here, two issues must be addressed, the selection of characteristics and savior babies.

On the one hand, the selection of characteristics of embryos raises issues about disabilities and sex selection. With regard to disabilities, the welfare of the child is of primary ethical concern, raising many ethical concerns such as in cases of that deal with the debate on wrongful life or on life not worth living.[88] With regard to sex selection, bioethics, public policy, and law intersect.[89]

On the other hand, in addition to the debate about selection characteristics of the embryo, there is an extensive debate on creating what is known as savior babies. The debate on savior babies raises ethical issues about instrumentalization and commodification. With regard to instrumentalization (treating a child as a means) is defined as the child being used for other's well being or the other's satisfaction.[90] With regard to commodification, there are different concerns to be addressed including price, interchangeable with other goods, and value. From the perspective of normative morality, commodification of the embryo should be denounced as wrong.[91]

IV. Newborn Genetic Screening.

Closely related to the ethical debate on prenatal screening is the debate on newborn screening, which requires examining two related topics: screening programs and screening consequences.

A. Screening Programs.

First, to understand screening programs, it is important to engage two pivotal issues: the national research framework and the future of genetic screening.

On the one hand, the national research framework for newborn screening deals with two essential elements: an overview of genetic testing and challenges of research for newborn screening. With regard to an overview of genetic screening, in the 1960s, a

simple blood test to detect a genetic metabolic disorder was developed; this was used to detect phenylketonuria a genetic disorder that can lead to retardation.[92] With regard to challenges of research, crucial issues deal with whether morbidity and mortality are reduced as a result of screening.[93]

On the other hand, the future of genetic screening needs to focus on expanded newborn screening and whole genome sequencing. With regard to expanded newborn screening, the emergence of new technology, tandem mass spectrometry, has created pressure to add numerous tests to the newborn screening.[94] With regard to the prospect of whole gene sequencing, the potential exists for integration with the newborn screening programs that could lead to unsought information and questions of meaningful informed consent.[95]

B. Screening Consequences.

Second, programs for newborn screening inevitably create concern about screening consequences. To discuss concerns about screening consequences, there are two areas of consideration, an overview of the problem and a consideration of disease ontologies.

On the one hand, an overview of the problem sheds light on two interrelated concepts, the origins and the successes of screening. With regard to origins, Robert Guthrie (d. 1995), made a breakthrough.[96] With regard to the successes, phenylketonuria screening has largely been a success story that celebrates the marriage of patient advocacy with concerned health professionals to promote screening.[97]

On the other hand, disease ontology can be best understood through pre-screening and post-screening. With regard to pre-screening, the understanding of medium-chain

acyl-coenzyme A dehydrogenase deficiency was very limited.[98] With regard to post-screening, several variants that were previously unknown have been identified. After screening, geneticists have a better understanding of diseases like medium-chain acyl-coenzyme A dehydrogenase deficiency and have adjusted treatment regimens.[99]

This chapter has considered major issues in reproductive technology that have significant applications for the Catholic ethical tradition. Catholic teaching engages each of them dynamically to develop its moral doctrine. This is based on emerging science, but also to indicate clearly where there appears to be wrongdoing from individual and social perspectives. The next chapter continues this analysis of engaging the Catholic Tradition with breakthroughs in science and medicine by examining emerging issues in regenerative technology.

V. Critique Based on the Ethical and Religious Directives.

The final section of the chapter presents a critique of the ethical analysis from the normative perspective of the *Ethical and Religious Directives for Catholic Health Care Services*.

Chapter 5. Regenerative Technology.

With the progress in human genetics, enhancement via germline genetic modification is replete with bioethical concerns. A general ethical landscape for assessing specific germline technologies has four related topics: genetic enhancement, germline modification, mitochondrial DNA, and gene editing with clustered-interspaced short palindromic repeats (CRISPR).

I. Genetic Enhancement.

The ethical debate on genetic enhancement focuses upon human progress and future generations.

A. Human Progress.

First, a consideration of the significance of genetic enhancement for human progress engages two foundational issues: human development and human nature.

On the one hand, discourse on human development highlights ethical dilemmas that arise and a consideration of historical enhancements. With regard to ethical dilemmas, ethics discourse revolves around goods or benefits. In these approaches, the key focus is eliminating any social harm that could arise from enhancements.[100] With regard to historical enhancements, society has benefited from what is construed as non-controversial enhancements such as literacy, the agrarian revolution, computer technology, and health care, etc.[101] All have offered benefit to humanity.[102]

On the other hand, to approach the meaning of human nature in a nuanced manner requires a consideration of its common characteristics combined with sensitivity to the precautionary principle. With regard to common characteristics, human nature involves a set of common characteristics differentiating human beings and other creatures.[103] With regard to the precautionary principle, there is an ethical responsibility to honor the concern of humanity overreaching its legitimate moral authority.[104]

B. Future Generations.

Second, the impact of germline genetic modification on human progress raises the question of influencing future generations focusing upon the significance of identity and perfection.

On the one hand, discussion about identity raises issues about superhuman enhancements and enhancements that deal with disease avoidance. With regard to superhuman enhancements, three moral concerns emerge: goals of medicine as incompatible with enhancement, the Positional Goods Argument (giving one person advantage over another), and the argument that enhancements generate inequality.[105] With regard to disease avoidance, the ethical debate revolves around therapy (healing a pathology), functionality (improving the human functioning), and transhumanism (changing human nature).[106]

On the other hand, discussion about perfection via genetic enhancement engages two pivotal issues: stewardship of nature and naturalism versus transhumanism. With regard to stewardship of nature, a central concern deals with non-malfeasance to future generations.[107] From this perspective of avoiding harm, stewardship entails an obligation about many interrelated issues: the use of natural resources, preservation of the environment, and oversight of the human gene pool.[108] With regard to naturalism versus transhumanism, the core debate revolves around the quest for perfection. These extreme versions of human development raise significant ethical challenges.

II. Germline Genetic Modification.

The ethical debate on genetic enhancement, in general, leads to the more specific focus on genetic germline modification that requires examining two related perspectives: the religious and secular perspectives.

A. Religious Perspectives.

First, two mainstream religious perspectives of germline genetic modifications are represented in the views of the Roman Catholic Church and traditional Protestant Christianity.

On the one hand, the views of the Roman Catholic highlight what is permissible and what is prohibited. With regard to what is permissible, several illustrative points can be made. Two theological issues need to be stressed. Modifying human genetics is directly tied to the person's good and raises concerns that are problematic.[109] With regard to what is prohibited several issues arise. First, because embryos are living human beings, any experimentation that is not therapeutic is illicit. Second, every individual human body has dignity thus it is not allowed to engage in cloning. And thirdly, personal dignity must be maintained hence attempting to alter human chromosomes or genetic inheritance must not be allowed.[110]

On the other hand, from the perspective of traditional Protestant Christianity, just as with Catholicism, there are issues that are prohibited and issues that are permissible. With regard to what is prohibited, Protestant Christianity is replete with cautionary tales limiting the embrace of acts that extend beyond natural limits.[111] With regard to what may be permissible, there is agreement that human nature was not created in its present form.[112] One intriguing possibility that Protestantism is open to considering regarding germline genetic modification is when it is adopted to increase resistance to deadly disease that impacts the human species.[113]

B. Secular Perspectives.

Second, the secular perspective on germline genetic modification revolves around discussions on justice and the common good, and also implications for risk and safety.

On the one hand, discussion on justice and common good raises issues that focus on social concerns and long-term impact. With regard to social concerns, germline genetic modification could be justified if it could make medical and technological modifications to solve potential problems.[114] But justice would require treatments to be made widely available.[115] There are different approaches to the discourse on justice, such as distributive, commutative, and rectification justice.[116] Equitable distribution of benefits is crucial for the common good.[117] With regard to long-term impact, with germline genetic modification the potential for good and harm is great.[118] Long-term impacts affect our common interests. Therefore, regulation of germline genetic modification is indispensable. An interdisciplinary approach is needed because of the complex interaction between genetics and ethics.[119]

On the other hand, accompanying discussion of justice, crucial concerns regarding risk and safety arise.[120] These concerns deal with differing approaches to germline modification and human-nonhuman chimera research. With regard to differing approaches, the most dangerous aspect of germline modification is the unintentional results that affect the species, even though restricting enhancement to a limited scale can diminish risk.[121] There are different approaches to the risk reduction of unintentional germline modifications, including total prohibition, implementing a risk-reducing principle, or using cautionary heuristics.[122] With regard to human-nonhuman chimera research, there is widespread consensus that denigration of human dignity would result

from germline modification that arises in chimera creations.[123] In sum, the concept of human dignity is crucial for evaluating the morality of these new genetic technologies.[124]

III. Mitochondrial DNA.

The previous sections on genetic enhancement and germline genetic modification delineate the ethical landscape for evaluating new genetic technologies that will impact future generations. Two recent technologies have emerged that are now considered in further detail: mitochondrial DNA and gene editing technology, CRISPR.

To discuss the ethics of mitochondrial DNA, the pivotal ethical topics require examining two related topics: the science of mitochondrial DNA and the ethical, social, and policy considerations.

A. Science of Mitochondrial DNA.

First, to understand the ethical debate on mitochondrial DNA, a discussion must address human reproduction as well as mitochondrial DNA biology and the mitochondrial DNA diseases and research.

On the one hand, fundamentals of human reproduction and the mitochondrial biology raise ethical issues related to propagation and mitochondrial DNA science. With regard to issues dealing with propagation, the ethical debate revolves around the point of fusion of an egg and sperm that create the zygote as the first step in human embryogenesis.[125] With regard to issues dealing with mitochondria DNA science, the focus is upon mitochondria being in nearly all cell types. Understanding the basic science is indispensable for ethical debate on mitochondrial DNA interventions.

On the other hand, giving attention to mitochondrial DNA diseases and research requires a focus on maladies and various techniques utilized. With regard to maladies, the

diseases of mitochondrial DNA are similar, manifesting themselves in respiratory chain activity, primarily in organs of the highest energy demand. Some of the maternally inherited mitochondrial DNA diseases are Leigh syndrome; mitochondrial encephalomyopathy, lactic acidosis, and stroke-like episodes; myoclonic epilepsy with ragged-red fibers; neuropathy, ataxia, and retinitis pigmentosa; maternally inherited diabetes and deafness; maternally inherited Leigh syndrome; and Leber hereditary optic neuropathy.[126] Research of mitochondrial DNA diseases has led to gene editing of somatic cells. With regard to various techniques for mitochondrial replacement, the main focus is on maternal spindle transfer and pro-nuclear transfer. Other techniques, such as polar body transfer are being explored.[127]

B. Ethical, Social, and Policy Considerations.

Second, an understanding of the science of mitochondrial DNA sets the stage for addressing ethical, social, and policy considerations. These considerations are in large part addressed in discussions of unintended consequences and the recommendations of the Institute of Medicine.

On the one hand, to assess the unintended consequences, two points must be considered: evaluating unknowns and predicting impact. With regard to evaluating unknowns, considerations need to be addressed: heteroplasmy, the mitochondrial DNA bottleneck, and mitochondrial evolutionary theory.[128] With regard to predicting impact, the science of mitochondrial genetics makes preclinical studies difficult.[129]

On the other hand, the Institute of Medicine recommendations indicate that with attention to impact and with proper criteria for research expansion clinical investigation of mitochondrial replacement technique should be allowed to move forward. With regard

to considering impact, mitochondrial replacement techniques should be considered if the following conditions are met: safety must be established, and risk to all parties must be minimized, especially to future children, the likelihood of success must be evident, investigations must be limited to women who risk transmitting severe mitochondrial DNA diseases, risk should be minimized to alleviate adverse health for pregnant mothers and fetus, investigators and centers have to have demonstrated expertise for this technology, investigation should be limited to male embryos for intrauterine transfer, and every possible risk of mitochondrial DNA-nuclear DNA incompatibility needs to be mitigated.[130] With regard to criteria for research expansion, the United States Food and Drug Administration must review and approve, with subsequent marketing of mitochondrial replacement techniques incorporating the following elements: transparency that maximizes public sharing of information, public engagement through the involvement of relevant stakeholders, partnership with other regulatory authorities in aiding the assessment of benefits and risks, maximization of data quality through cross-referencing and pooling, circumscribed use by limiting the utilization of the technology to individuals and settings for which it's approved, and long-term follow-up with periodic review must be a requirement.[131]

IV. Gene Editing with Clustered-Interspaced Short Palindromic Repeats (CRISPR).

Closely related to the mitochondrial DNA ethical discussion is the debate on clustered-interspaced short palindromic repeats (CRISPR). This is gene editing technique targeting and modifying DNA. The pivotal ethical discussions on clustered-interspaced short palindromic repeats address two related topics: the science of genome editing and the ethical, social, and religious concerns.

A. Science of Gene Editing with CRISPR.

First, to appreciate the science of genome editing with CRISPR requires understanding of its history and its methodology.

On the one hand, in the historical development of CRISPR, two perspectives are helpful, biological breakthroughs and the current status of science. With regard to the breakthroughs in biology, CRISPR emerged from the new era of biology with the development of recombinant DNA technology in the 1970s. With regard to the current status of science, a major development occurred in 2010 when observing that the CRISPR system could recognize specific patterns of DNA from foreign invaders. In 2013, CRISPR successfully modified the primary mechanism of DNA. Because of that success, it has become a powerful tool that can now reliably cut human genome DNA at any location.[132]

On the other hand, to properly discuss the methodology of CRISPR two points are involved: tools for genome editing and its potential. With regard to the tools for genome editing, the methodology was by targeted molecular machines. With regard to the potential of CRISPR, experts believe these advances could have wide-ranging clinical applications with the potential to prevent or cure a variety of diseases.[133] The simplicity of this technology drastically reduces the time for conducting genome experiments.[134] The ethical debate on this technique will expand in the years ahead as treatments emerge.

B. Ethical, Social, and Religious Concerns.

Second, the concerns about CRISPR technology need to be discussed from the perspective of social and ethical dimensions as well as from the religious perspective.

On the one hand, from social and ethical perspectives, CRISPR raises concerns about impact and regarding the need for regulation. With regard to impact, the CRISPR approach to 'reprogramming DNA' raises similar concerns to those of genetic manipulation in general. Most notable of the concerns are the passing on to subsequent generations deleterious impacts on the human genome.[135] Before this technology can be utilized for germline modification, important knowledge needs to be gained regarding human genetic interaction in the interplay between diseases.[136] With regard to the need for regulation of this technology, it is crucial because of the potential for exploitation in non-therapeutic uses, off-target modifications, and embryonic screening.[137]

On the other hand, from the religious perspective, this technology raises significant concerns about dignity and respecting the unitive and procreative connection in human reproduction. With regard to the maintenance of dignity, a distinction must be made between editing for therapeutic purposes and enhancement to augment human capacities.[138] With regard to respecting the connection between the unitive and procreative aspects of human reproduction, the Catholic Church insists on not breaking that connection.[139]

This chapter has explored the ethical debates on the emerging regenerative technologies. The next chapter moves to address technological issues that arise at the end of life.

V. Critique Based on the Ethical and Religious Directives.

The final section of the chapter presents a critique of the ethical analysis from the normative perspective of the *Ethical and Religious Directives for Catholic Health Care Services.*

Chapter 6. On Death and Dying.

Throughout history, the attitudes of death and dying have transformed gradually, shifting focus from the dying and their families to the role of the physician and the health care team. As a result, the dying process has become rife with ethical dilemmas. To adequately discuss death and dying requires examining three related topics: changing attitudes to death and dying, the meaning of medical futility, and the withdrawal of life-sustaining treatment.

I. Changing Attitudes towards Death and Dying.

Death is the final journey all must take. To discuss the changing attitudes to death and dying, two areas elicit attention: the contemporary characteristics of death and dying and related philosophical approaches.

A. Characteristics.

First, contemporary characteristics of death and dying can be revealed in discussions about the locus of control and about accompanying rituals.

On the one hand, discussions about the locus of control tend to revolve around the meaning of a tame death, and around prolonging life. With regard to the meaning of a tame death, it can be a kind act of nature. Society has moved from the time when death was not a struggle; it was part of life. Philippe Aries refers to this perspective as "tamed death" or death that comes with natural warning signs.[140] A long lingering death was very unusual. People typically died of disease with rapid onset and a quick end.[141] With regard to the prolongation of life, there can be inappropriate approaches that resist the dying process as a natural phenomenon. Today's sophisticated medical technology can lead to

unjustified struggle against death in so far as health care is concerned as a master of death.[142]

On the other hand, discussions on the locus of control of death regarding the use of medical technology need to be situated within a broader context that respects rituals around death. With regard to the historical developments, as the locus of control of death shifted over the centuries, so did the rituals regarding death. For centuries, there was simplicity about the rituals.[143] As life expectancy began to shift, so did the view of death, the "tame death" came to an end due largely to the rise of scientific medicine. In the 1900s, death was taken out of the hands of families and put in the hands of doctors and medical institutions.[144] With regard to the evolution of the rituals around death, by the 1800s, the rituals of mourning became more public. As a result, mourning developed a double purpose, serving as a period of sorrow out of respect for the family while allowing for the dissipation of grief.[145]

B. Philosophical Approaches.

Second, the changing characteristics of dying over time have been accompanied by different philosophical tenets about death. Throughout history, as attitudes and customs towards death and dying changed, two philosophical approaches emerged to guide the dying process, one being physician-centered, the other being patient-centered care.

On the one hand, for the philosophical approach that is physician-centered, two interrelated issues are important: the meaning of the Hippocratic tradition and the role of paternalism and beneficence. With regard to the Hippocratic tradition, in taking the Hippocratic oath, physicians promise to act for the good and keep their patients from

harm. This Oath requires physicians to use their skills not as they would prefer but for human benefit.[146] With regard to paternalism and beneficence, they became the norm in the early 20th century. In this philosophy, the physician always knows best.[147] Medical paternalism ignores the patient's viewpoint and can focus on the cure of disease, at times leading to an inappropriate medical management of death.[148]

On the other hand, for the philosophical approach that is patient-centered, the focus is on patient autonomy and the accompanying conflict that can arise. With regard to focusing on patient autonomy, a tidal wave of change has occurred in medical ethics starting in 1965, shifting focus from the physician to the patient in decision-making.[149] With regard to the conflict that results from this new focus on autonomy can be an excessive or reflexive medical deference to patient autonomy.[150]

II. Medical Futility.

The discussion above on changing attitudes on death and dying offer insight into the ethical debate surrounding medical futility. The discussion over medical futility is fraught with controversy. To discuss medical futility requires examining two related topics: the debate about the meaning of futility and the goals of medicine.

A. Futility Polemic.

First, to clarify the meaning of medical futility, the ethical debate revolves around the definition of futility and the definition of rationing.

On the one hand, the definition of medical futility can be clarified by considering the purpose of treatment and by looking at an example of a futility policy, specifically the Texas Advance Directives Act. With regard to the purpose of treatment, clinicians need to recognize when interventions offer benefit. Hippocrates (d.375bce) stated that

physicians should not treat those who are overmastered by their disease.[151] To deal with situations of futility, three concepts are essential. First, treatments that are ineffective or harmful to patients are not obligatory. Second, physicians must engage in dialogue concerning futile treatments. Thirdly, physicians must convey concern even if there is no cure.[152] With regard to the policy enunciated in the Texas Advance Directives Act (September 1999), it became law to regulate end-of-life futility in the state of Texas. The law allows the physician to practice according to their conscience and the law seeks the good of the patient by preventing a prolonged dying process.[153]

On the other hand, discussing of medical futility needs to be distinguished from rationing. With regard to defining rationing, it needs to be separated from futility because they are very different ethical concepts. Futility deals with continuing treatment that has no benefit. Rationing is defined as withholding a treatment that does have a benefit. Limiting access to beneficial health care services both explicitly and implicitly rations health care resources. The core ethical debate is not whether health care can be rationed but how it is rationed, by whom, and to what degree. With regard to the purpose of rationing, it should be understood within the context of the organizational stewardship of scarce resources in health care.[154]

B. Compassionate Goals of Medicine and Health Care.

Second, the debate on medical futility connects the meaning of futility with the goals of medicine. To understand the goals of medicine when facing situations of medical futility, two issues must be addressed: the meaning of compassionate succor and how to deal with end-of-life dilemmas.

On the one hand, the meaning of compassionate succor refers to situations that deal with the prevention of disease and prevention of untimely death. With regard to situations dealing with the prevention of disease, compassionate succor has three roles. First, it is better to avoid disease. A physician's duty is to help patients stay well. Secondly, there can be a beneficial economic consequence for patients and society by helping reduce chronic disease. Thirdly, the public at large, as well as the medical community, needs to be aware that the preventive health care has significant benefits and needs emphasis.[155] With regard to prevention of untimely death, a goal of medicine is the prevention of premature death. In medicine today, its first aim should be to reduce premature death. The secondary purpose is proper care and support for those whose death is not premature.[156]

On the other hand, the goals of medicine raise issues regarding end-of-life dilemmas. End-of-life dilemmas raise ethical issues about balancing criteria of burden versus benefit and about the sanctity of life. With regard to balancing criteria of burden versus benefit, patients are now often subjected to prolonged lives and acute complications, forcing them to make decisions about how vigorously to treat and when it is permissible to withhold or withdraw life-sustaining measures.[157] With regard to the sanctity of life, the determination of the balance burden and benefit must demonstrate respect for life (used interchangeably with the religious concept of sanctity of life), thereby respecting the human person.[158]

III. Withdrawal of Life-Sustaining Treatment.

Related to the above discussion regarding attitudes to death and medical futility, is the ethical debate around the withdrawal of life-sustaining treatment. This discussion

requires consideration of two related topics: medically assisted nutrition and hydration and the relief of suffering at the end-of-life.

A. Medically Assisted Nutrition and Hydration.

First, medically assisted nutrition and hydration are especially significant as a medical intervention at end-of-life and for patients in a persistent vegetative state.

On the one hand, at end-of-life, the ethical debate on medically assisted nutrition and hydration revolve around clarifying its medical purpose and how these encounter cultural pressures. With regard to medical purpose of assisted nutrition and hydration at the end of life, two reasons are typically cited for using this technology: to improve fatigue and to avoid 'starving to death.'[159] With regard to cultural pressures, family members often feel helpless in the face of disease progression.[160] Often the conversation around nutrition and hydration has more to do with acceptance of dying. When used inappropriately due to cultural pressure, artificial feeding can cause needless pain-and-suffering and prolongation of death.[161]

On the other hand, medically assisted nutrition and hydration are used for patients in a persistent vegetative state. With regard to definition, a persistent vegetative state is a clinical condition of complete unawareness of self in the environment, accompanied by sleep-wake cycles, with either complete or partial preservation of brain in brainstem function. Patients in a persistent vegetative state show no evidence of sustained, deducible, purposeful, or voluntary behavioral responses.[162] With regard to moral direction about providing persistent vegetative state patients with artificial feeding, in a papal allocution March 20, 2004, Pope John II is helpful. He stated that hydration and nutrition constitute a morally ordinary treatment for persistent vegetative state patients

and that foregoing would be considered 'euthanasia by omission.'[163] The United States Conference of Catholic Bishops interpreted this papal statement by explaining "certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory."[164]

B. Relief of Suffering.

Second, the withdrawal of life–sustaining treatment is designed to address the relief of suffering at the end-of-life. This raises specific ethical concerns regarding palliative care and assisted suicide.

On the one hand, to address palliative care, two interrelated concepts need consideration: care at end-of-life and palliative sedation. With regard to care at the end of life, patients near the end-of-life often have multiple transitions; these transitions can cause medical errors, poor care planning, and lack of coordination and continuity of care.[165] To aid in the alleviation of these obstacles, palliative care provides pain control as well as providing relief from other distressing symptoms.[166] With regard to palliative sedation, symptom control (pain, dyspnea, shortness of breath, restlessness, and nausea/vomiting) is one of the reasons for not having a good death. [167] When symptoms are not controlled, palliative sedation has been approved and endorsed by the American Medical Association, American Nurses Association, the American Academy of Pain Medicine, and the American Academy of Hospice and Palliative Medicine.[168] Rarely is it necessary to sedate patients to the point of sleep to accomplish symptom control. But if necessary, sedation for the control of intractable suffering in an imminently dying patient is humane, appropriate, and medically acceptable. Palliative sedation therapy is the use of

specific sedative medications to relieve intractable suffering from refractory symptoms.[169]

On the other hand, assisted suicide raises issues related to symptom control and patient autonomy. With regard to symptom control, the predominant reason for requesting physician-assisted suicide is symptom control.[170] With regard to patient autonomy, paradoxes have surfaced in the argument about physician-assisted suicide.[171]

This chapter has extended the discussion of medical technology from the start of life to address end of life dilemmas. The contribution of the Catholic Tradition is to be highly attuned to protecting the dignity of the patients, especially at the end-of-life and even when they request medical technology for assisted suicide. The Catholic Tradition urges the use of medical technology to alleviate patient suffering without intending their death.

IV. Critique Based on the Ethical and Religious Directives.

The final section of the chapter presents a critique of the ethical analysis from the normative perspective of the *Ethical and Religious Directives for Catholic Health Care.*

Chapter 7. Conclusion.

This proposed dissertation has presented an explanation of the contribution that the normative approach of Catholic teaching for resolving ethical dilemmas regarding medical technology in Catholic health care. The *Ethical and Religious Directives for Catholic Health Care Services* have provided authoritative and normative guidance on moral issues while grounding us in three concepts: social, pastoral, and professional responsibility. This normative framework for Catholic health care ethics is utilized to discuss ethical decision-making models that are consistent with Catholic ethics. The

following topics are examined in light of these foundational principles: moral agency and organizational ethics, the competence of patients for making end-of-life decisions, and the role of clinical ethics consultation services. Additionally, reproductive technology is examined in light of the normative guidance, addressing these topics: the embryo and personhood, stem cell technologies, prenatal testing, and newborn screening. Catholic teaching engages these areas of emerging science to indicate where there may be wrongdoing from individual and social perspectives. Additionally, in light of Catholic teaching, emerging issues are examined in the area of regenerative technology: genetic enhancement, germline modifications, mitochondrial DNA, and gene editing with clustered-interspaced short palindromic repeats. Finally, the technological issues that arise at the end-of-life are addressed in light of Catholic teaching, focusing on these pivotal topics: changing attitudes on death and dying, medical futility, and withdrawal of life-sustaining therapies.

The analysis will emphasize that the commitment to promote and defend dignity of the human person from the moment of conception until natural death has remained at the forefront of the discussion.

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Chapter 2. Normative Framework of Catholic Health Care Ethics.

To discuss the normative framework of Catholic health care ethics requires examining two related topics: the *Ethical and Religious Directives for Catholic Health Care Services* and practical ethical principles for Catholic health care.

I. Ethical and Religious Directives for Catholic Health Care Services.

The normative framework of Catholic health care ethics is presented in the *Ethical and Religious Directives for Catholic Health Care Services*. The Ethical and Religious Directives are a body of moral principles that introduce the teaching on the ethical standards of behavior and provide authoritative and normative guidance on moral issues in health care. The Ethical and Religious Directives are grounded on three leading concepts: social responsibility, pastoral responsibility, and professional responsibility. The Ethical and Religious Directives are designed to address the challenges raised by medical technology in order to provide normative guidance for ethical decision-making when trying to resolve complex ethical dilemmas.

With the Catholic Church's commitment to the mission of healing and the ever-changing health care delivery, a body of moral principles has emerged from the Church's teachings. The Ethical and Religious Directives have the purpose of affirming ethical standards of behavior. They also provide authoritative guidance on certain moral issues. The Ethical and Religious Directives do not offer guidance on every detail of all the complex health care issues but are periodically reviewed. This review is in light of maintaining the true dignity of the human person. It is often argued that science and faith contradict each other but both are grounded in truth and freedom. As knowledge and technology expand, it is each individual's task to form a correct conscience guided by

moral norms. The Ethical and Religious Directives should be followed with deliberation and often need to be considered on a case-by-case basis. The Ethical and Religious Directives strike the precarious balance between absolutism and relativism.

In sum, the Preamble and the Introduction to the *Ethical and Religious Directives for Catholic Health Care Services* highlight the need for an ethical framework to critically engage and normatively guide the use of medical technology today. Hence, the main sections of the Ethical and Religious Directives are designed to present a cogent and consistent ethical framework that is adopted throughout this dissertation to provide a critical appraisal of the ethical debate on medical technology. The ethical framework combines the integral relation between human dignity and social responsibility with a set of ethical principles to provide normative guidance. This integral relation and its accompanying ethical principles are discussed in the next two sections to present a robust foundation for the analysis in the subsequent chapters. The integral relation between human dignity and social responsibility in the Ethical and Religious Directives are described in terms of social responsibilities of Catholic health care services (Part One of the *Ethical and Religious Directives for Catholic Health Care Services*), the Pastoral and Spiritual Responsibility of Catholic health care (Part Two of the *Ethical and Religious Directives for Catholic Health Care Services*) and the professional-patient relationship (Part Three of the *Ethical and Religious Directives for Catholic Health Care Services*). Each of these is considered in turn.

A. Social Responsibility.

To address the social responsibility of Catholic health care, the *Ethical and Religious Directives for Catholic Health Care Services* emphasize that the "complex

health care system confronts a range of economic, technological, social, and moral challenges."[1] This dissertation focuses upon the technological and moral challenges that present themselves. The response of Catholic health care to these challenges "is guided by normative principles"[2]. The foundation for these principles is the integral relation between human dignity and social responsibility. This integral relation builds upon a biblical background to guide moral responsibility in health care, as discussed in the following two sections.

1. Biblical Background.

The Bible emphasizes that human dignity and vulnerability must be understood in relationship to God and in relationship with others. This reciprocal relationship highlights the reciprocity between God's invitation and human response.

God's Invitation and Human Response.

The biblical concept of the person is defined in terms of word and response enabled because of the human being made in the image and likeness of God. In light of that image and likeness of God we are assured the sacredness of all human life.[3] The person is a speaker of the word and the hearer of the word because we are addressed by God and given inalienable dignity. In the Old Testament, the widows and orphans had no one to defend them thus they were given protection under the law; consequently they maintained an inviolable dignity. In the Old and New Testament, dignity is based upon the relationship with God not on the autonomous and inviolable selfhood. Because of that relationship with God we too are called to maintain a mutual respect for those most vulnerable.[4] In the earliest writings, God gives human dignity and He unconditionally accepts, affirms, sustains, and supports that dignity. In the Synoptic Gospels, Jesus

invites those who were sinners and thought to be absent of dignity into his company.[5] Jesus is the greatest example for us, thus we must become animated advocates for the most disadvantaged and vulnerable.[6] As imitators of Christ, we are mandated to care for the needs of the poor as well.[7]

Dignity is also characterized by the human response to God's invitation. Dignity is intrinsic to every human being and cannot be given or taken away by the state, human laws, or another human being. Integrated with the soul, dignity is given by God at conception and is an aspect of personhood. Man's life is a wonderful gift that should never be disrespected or used as a way to accomplish another's selfish end. Man was created in God's image and likeness and has an eternal place in heaven prepared for him. Man is endowed with the capacity to accept or reject God and our relationship with others. Respect for human dignity means that everyone must have what they need to lead a truly human life: food, clothing, shelter, the freedom to choose a state of life and to establish a family, the right to education, employment, a good reputation, respect, appropriate information, action in good conscience, protection of privacy, and religious freedom. God made us into one family, and we should treat one another in the spirit of community.[8] Thus we are called to contribute to man's common good.[9]

Understanding human dignity and its origin from God provide the foundation for our relationship with others. This relationship with others highlights the importance of objective dignity and its recognition of human vulnerability.

Dignity and Vulnerability.

Historically, in the classical time of Rome, dignity was confined to individuals and never applied to humans in general. From the early Christian writings, humans

possessed dignity because they are unique from other creatures. Unconditional forms of dignity continued during the Renaissance period when dignity was opposed to misery. After the Renaissance, a new form of dignity called subjective dignity was formulated. Based on subjective dignity, it was argued that God says that all created things are constrained within prescribed laws of man who may choose the limits of his nature. Man has the opportunity to fashion himself in whatever shape he chooses. Immanuel Kant introduced another form of dignity during the age of reason: objective dignity. This means that rational beings have dignity as long as they are capable of moral action. In modern times, an increasing emphasis on respect for dignity has taken place and even adopted into the charter of the United Nations. This understanding of objective dignity highlights the reality of human vulnerability.[10]

Understanding dignity in relation to others not only highlights the objective nature of human dignity but also emphasizes the recognition of humans as being vulnerable. This is especially important for health care. Dignity should be viewed from the perspective of policy principle as well as the view that the value of dignity is a standard of patient care. These two concepts are not mutually exclusive. Human dignity has emerged as an obligation to be recognized that all people have a basic right. Human dignity is not viewed as merely a metaphysical hypothesis but emerges as an indispensable basis for the fair functioning of all of human society. Humans are granted dignity because of their capability to be kind, understanding, self-aware and loving. Dignity should be a standard of health care reflecting the understanding of the patient as a vulnerable person relates to the dynamic of interaction between patient and health care

professionals. Because of the vulnerability of the patient, great care needs to be exercised to promote the dignity of the patient.[11]

Briefly, with the biblical background of dignity highlights the reciprocal relation with God and with others. This presents the foundation for understanding moral responsibility in health care.

2. Moral Responsibility in Health Care.

Moral responsibility in health care emphasizes the importance of social accountability and natural law as exemplified in the *Ethical and Religious Directives for Catholic Health Care Services*.

Accountability.

Moral responsibility highlights two related components of social accountability: the common good and professional accountability. Sociality is a dimension of the human person. Man is a social individual, a member of society but only as a being, infinitely transcending the society. Humanity is worthy of being called human if a society of persons is founded on the principle of common good. The human person has the capacity for inter-relations and communication. The human social dimension is based on human personhood. We have obligations and responsibilities to always respect the rights of others and to work for the common good. Man creates society; man is not created by society. Man must fulfill himself by being a full participating member of human society.[12]

To heal the whole person, health professionals must understand not only what disease is attacking the body but also what that disease is doing to the patient as a spiritual being. Illness is a spiritual event disturbing both the soul and the body. Spiritual

questions raised at this time can be of meaning regarding value and relationships. Health professionals have to address these questions themselves before they can help their patients. The transcendent is present in the midst of daily practice. The transcendent can be found not only in conversations about spiritual dimensions with patients but in the moments in which meaning and value can be communicated to the patient. Barriers can stand in the way to the awakening of health care as a spiritual enterprise. Scientific reductionism, the denying of the transcendent, and the industrialization of health care threaten the restorative relationship that can begin when one person feels sick and another, skilled and socially authorized person provides support.[13]

Social accountability, with its related components of respecting the common good and inspiring health professionals, fosters moral responsibility especially in the health care environment that is illustrated by the Ethical and Religious Directives. *The Ethical and Religious Directives* arose from the development of ethical norms that express the Church's teaching on medical and moral matters.

Natural Law.

Engaged professionals in health care have always tried to maintain the spirit of Christ in the ministry and in accord with the church's teachings. Theologians beginning in the 16th century engaged ethical issues in the practice of medicine. These included the elongation of life and methods to determine when death occurred. Standards of care were applied to treatments and general norms emerged. Written directives were established because of the development of Catholic health care and the need for guidance for serious moral issues. Initially these directives were rather legalistic, not explaining the church's

teaching or scriptural basis but merely laid out rules. Recent additions of the Catholic health care directives have adopted a more theological approach to ethical guidance.[14]

The Ethical and Religious Directives have emerged as a body of moral principles of the Church that are applicable to ever-changing health care. The Ethical and Religious Directives have two main purposes: (1) to provide guidance for health care today and (2) they set forth the ethical standards that flow from the church's teaching about dignity of the human person. The Ethical and Religious Directives are helpful for health care professionals and also offers guidance on health care decisions of the Catholic faithful. Natural law, knowing God through reason in addition to knowledge through biblical revelation, and the authority of the Church Magisterium provide the foundation for the moral teachings. The Ethical and Religious Directives call for each person to form a correct conscience. The Ethical and Religious Directives should be considered on a case-by-case analysis. These directives were not developed with absolutism in mind nor were they developed from a relativist's perspective.[15]

In sum, human dignity and social responsibility highlight the contribution of the biblical foundation for moral responsibility in health care. The combination of our relation with God and others (based on the Bible) enables us to understand the social accountability of the Ethical and Religious Directives as applications of our moral responsibility.

B. Pastoral Responsibility.

The foundational concept of social responsibility is accompanied with the concept of pastoral responsibility. To fulfill our pastoral responsibility, two areas must be expounded upon: spiritual responsibility and pastoral care.

1. Spiritual Responsibility.

To fulfill the pastoral responsibility we must recognize and attend to the spiritual dimension and the spiritual struggles that are brought to the struggles of the patient in health care. Both will be discussed in this section.

Spiritual Dimension.

A community of healing and compassion incorporates not only the treatment of a malady but encompasses the psychosocial and the spiritual dimension of the human person.[16] Without health of the Spirit, little hope for healing the whole person can be achieved through focused technology alone.[17] Spiritual dimension or commonly referred to as spirituality, has not stopped evolving in its meaning. Spirituality has a "fuzzy" construct and is not purely an academic question.[18] Spirituality can be defined as a "the search for the sacred." The heart and soul of spirituality is the sacred, a higher power or divine being. For others the sacred is in the broader sense, such as objects, music, vegetarianism, virtues, or visions. The sacred can be aspects of life that have divine character or represent divinity as well as the concept of God, the divine or transcendent reality.[19] Problematic of the divine is that it is inherently mysterious, elusive, and indescribable and language, symbols, and stories fail to capture its essence. Regardless of our understanding or varying ways of imagining at the core of the sacred is God, divine beings, or a transcendent reality.[20]

To aid our understanding and to become communities of healing and compassion, we must understand that even though God is central of the sacred, sacred matters encompass other aspects of life.[21] Personal illness or injury, illness or death of a family member, can be great life stressors perceived to be violations of the sacred. Spiritual

violations impact people emotionally and physically, these may be viewed as sacred losses. The sacred losses can elicit anger and rage as well as sadness and depression.[22] Even guilt may be a manifestation of the personal violations of the sacred. The spiritual integration of an individual will have an impact on how well these individuals cope. Holding on to the sacred is the first choice in trying to cope with these violations.

Spiritual Struggles.

Spiritual struggles may emerge if holding on to the sacred seems no longer viable. But two major ways of spiritual coping will emerge: one is to conserve the sacred while the other transforms the sacred.[23] To maintain their relationship with the sacred, various methods of coping can be used to deal with threatening situations. These coping methods come in a variety of shapes and forms. In the midst of crisis, these methods help sustain people psychologically, socially, physically, and spiritually. Some of these methods of spiritual coping are: (1) reevaluating a stressor as to its potential benefit, (2) seeking love and concern from the sacred, (3) seeking a connectedness with the transcendent, (4) providing spiritual support to others, (5) seeking a partnership with the transcendent, and (6) using ritual for spiritual cleansing. Spiritual struggles can be a sign of disorientation, tension, and strain. Within spiritual struggles there are three types: interpersonal, intrapersonal, and the divine. Interpersonal spiritual struggles involve conflicts with families, friends, and congregations.[24] The intrapersonal struggles question one's own value, efficacy, or spiritual purpose.[25] And finally, spiritual struggles involve strain between the individual and the divine. Stressful life events can throw a pall over the view that God is a loving all-powerful being who ensures only good things for us.[26]

Spiritual transformation may occur as a result of stressors. The place and character of the sacred in a person's life may fundamentally change, as well as the path to the sacred. Spiritual transformation can be a painful process but can be the normal part of the search for the sacred. Transformation of the spiritual can end in failure but success as well and the right of passage may feel empty and meaningless. Spirituality may ebb and flow over our lifespan and can become downright puzzling but a very normal dimension of our human experience. It is simply part of what it means to be human.[27]

2. Pastoral Care.

To fulfill our pastoral care responsibility, we first have to understand and appreciate the spiritual dimension of the human person. In that understanding and appreciation we must then minister and shepherd the patient within our care.

Ministry.

The human person was created by God to be in relationship and this relationship continues by God's hearing us, remembering us and meeting us in our relationships with one another. Pastoral care is a ministry that occurs in a Christian community through remembering God's action for us. Additionally, hearing and remembering those we minister to as we remember who we are as God's people.[28] A natural thing for us is caring for one another because we are created for fellowship with God and one another.[29] The human beings deepest need is to be cared about by God and in God's name care for others. In that caring for others, we must have an attitude of protectiveness and solicitude.[30] An additional characteristic of a caring attitude is supportiveness. Supportiveness is acknowledging the worthiness and integrity of another in their own

right referring to qualities of warmth, empathy, and unconditional positive regard for another. Encouraging is the final quality important to caring.[31]

Shepherding is a particular kind of caring relationship and attitude, one that we all are called to cultivate towards others.[32]

Shepherding.

The foundation of a shepherding relationship begins with empathy. Empathy is the capacity to know and feel others feelings. The total acceptance of others with whatever feelings they may exhibit is essential in establishing a caring relationship.[33]

Empathy requires discernment of how another is feeling, a sense of feeling with, requiring appropriate distance and appropriate detachment.[34] Another foundation of the shepherding relationship is that of genuineness and humility. This involves offering ourselves as finite, fallen, redeemed people, and only able to help others by God's grace and love. Simply stated, being humble and grateful is the essence of being genuine. It is more than consistency, integrity, and wholeness. Being transparent to the One in whom we have our being is the chief constituent of genuineness.[35] Additionally, another basic of the shepherding relationship is that of respect. Respect is valuing the dignity and worth of one of God's creations. With respect, there is no obligation to feel the way they feel about things, to agree with them in their way of thinking or decisions, or are we to agree with their every action. But we are to have regard for and protect their rights as human beings.[36] An unconditional positive regard is an obligation of every caregiver. People must set aside their prejudices, animosities, and their inclination for judgment in order to minister and be a good shepherd.[37] Hope tempered with realism, another characteristic of good shepherding, is in anticipation of the positive change in the external conditions as

well as the inward process of reacting to them. Hope must prevail to have any semblance of healing but hope is more than a basic outlook or attitude. Hope is alive in us already; it does not have to be created. Hope is derived from a desirable self-image, healthy self-esteem, and belief in the ability to exert influence on the world. [38] The most helpful and appreciated skill to be someone's shepherd is the skill of listening. We must develop the skill of genuine interest in what a person wants and needs. Rather than being an obligation, when we listen from interest we are then most able to respond thoughtfully and appropriately.[39] Listening runs against our self-centeredness but in doing something for another we have to take a basic attitude that we are going to open ourselves and actively listen to the care receiver. To hear what is beyond, behind, and beneath the surface is the ultimate aim of listening. Good listening is vital to good shepherding.[40]

C. Professional Responsibilities.

In addition to foundational concepts of social and pastoral responsibility, the *Ethical and Religious Directives for Catholic Health Care Services* also address the basic concept of professional responsibility. In the concept of professional responsibility that addresses the patient-physician relationship, three areas stand out: informed consent, surrogate decision-making, and the need for a conscience clause that provides protection for physicians. Each is considered briefly.

1. Informed Consent.

In this discussion of informed consent, purpose along with components and the effective process will be engaged.

Purpose.

Historically, informed consent as it is practiced today is a relatively new arrival in medical ethics. Now, informed consent is central to professional-patient relationships.[41] Informed consent has often remained controversial because as practiced questions are raised as to whether it is really an informed choice by the patient. Because of past abuses, controversial cases, and the growing of patient rights movements as well as a skeptical attitude of patients toward medicine, the importance of informed consent may be more assumed than actually practiced.[42] The justification for informed consent is for the safeguard of the patient's dignity and autonomy. Autonomy, being one of the four parts of "common morality" shared by "all morally serious persons," is the ability to make independent decisions.[43] To better understand the professional-patient relationship, autonomy should be looked at as the kind of contract where the patient is empowered to play an active equal part in the decision-making about their treatment. It has been argued that this kind of contractual model can present dangers if fulfilled to the letter of the contract but no more or conversely if one performs every possible test and procedure with unlikely benefit. Even so, this contractual model has significant advantages over the paternalistic model of the past.[44]

Informed consent has become the primary tool for protecting the legal rights of patients and in guiding the ethical practice of medicine. Legally, informed consent protects patients against assault and battery as well as safeguarding the rights of autonomy, self-determination, inviolability, and dignity.[45] The ethical purpose of informed consent is intended to shift the decision-making away from the physician toward the patient. Informed consent should not be an event but a process that continues

as long as choices remain. All too often the consent form is confused with the consent process.[46] In the informed consent process four basic elements are necessary: (1) the decision-maker has capacity to make decisions, (2) the physician must disclose sufficient detail for the decision-maker to make an appropriate choice, (3) the decision-maker displays understanding of the information given, and (4) the decision-maker should be allowed to freely agree.[47]

Components and Effective Process.

Five components should be included in the conversation regarding informed consent: the diagnosis, the treatment plan, the risks and benefits of the treatment, any alternative treatments, and the risks and benefits of declining treatment.[48]

Well-documented limitations complicate the practice of informed consent. These limitations include patient comprehension, patient use of disclosed information, autonomy, and the pressure placed on health care providers. During the informed consent process patients often remember very little of the information disclosed. Their level of comprehension is overestimated because of factors such as age, education, intelligence, cognitive function, and anxiety all deleteriously affecting the patient's understanding.[49]

Even though patients are uniformly interested in learning about their proposed procedures, some patients make decisions in a linear, rational fashion considering the risk and benefits while others base their decisions on intuition or instincts. Social forces can undermine the effectiveness of informed consent as well.[50] Rather than exercising their autonomy independently many patients prefer to delegate their decisions to others or make decisions collaboratively with their support systems.[51] Clinical schedules are extremely busy thus making a rigorous informed consent process very difficult. Health

care administrators rarely recognize or accommodate for such time commitments.[52] Despite the consensus that informed consent should pervade medical practice, physicians rarely meet minimal standards of disclosure in obtaining informed consent. The consent process is primarily viewed as a tool for building trust rather than a technique for decision-making.[53]

The move from physician-centered to patient-centered decision-making has been accomplished with regards to the law and ethics of informed consent. There are increasing concerns that the pendulum may have swung too far by mandating the patients' self-determination must be exercised in a very particular way.[54] To ally this concern, there is a growing focus on a shared process of decision-making. This would be a process that emphasizes the critical importance of the patient's input while recognizing that it should be tailored to each patient's ability and interest in participation. This process recognizes the physician's contribution to the decision, which is important and deserves its own respect.[55] This process also recognizes that medical treatment is a partnership between the patient and clinician and there is moral responsibility assumed by both partners. Neither can dominate the decision nor can they abrogate.[56] Another approach regarding informed consent pertains primarily to those decisions that involve choices about the goals of medical treatment. Interpretations of informed consent that are overly rigid confuse the roles of the physician. Eliciting patients values allow the physician and the patient to reach agreement. Once agreement of the goals has been reached then the physician is free to make appropriate medical decisions.[57]

The practice of informed consent can be complex and confusing requiring flexibility to accomplish goals. These goals are legal ones such as protecting patients'

rights, ethical goals pertaining to autonomous decision-making, administrative goals assuring efficient healthcare, and finally interpersonal goals of building trust needed to accomplish medical interventions.[58] To accomplish these goals the following suggestions are for optimizing the clinical informed consent process:

1. Make a practice of involving patients in making medical decisions.
    a. Be aware of patients' preferences and their unique decision-making styles.
    b. Openly address the risks and benefits, alternatives, and what is to be expected.
    c. These practices will aid in:

        Patients' decision-making

        Free choice devoid of undue influence

        Patients' understanding
2. Determine the goals of care.
    a. Clarification of goals of care may be needed.
    b. The more complex the decisions the more explicit the discussion.
3. Allow the informed consent process to fulfill its varied purposes.
    a. Legal to protect patients' rights.
    b. Ethical to support autonomy and dignity.
    c. Administrative to promote efficient health care.
    d. Interpersonal to accommodate and build trust.
4. To ensure understanding and permanence document electronic medical record including:
    a. Consent forms.
    b. Education materials.

c. Notes describing the process.

d. Decision aids utilized in the process.[59]

This suggested process serves as a pragmatic approach to facilitate and document the involvement of patients in medical decision-making. These practices of establishing informed consent of patients making medical decisions demonstrate the ethical spirit of informed consent.[60]

2. Surrogate Decision-Making.

In keeping with the consideration of the professional-patient relationship in the *Ethical and Religious Directives for Catholic Health Care Services*, it is imperative that a discussion of surrogate decision-making takes place. In surrogate decision-making, two areas will be discussed: the function and naming and advising.

Function.

Traditionally, physicians have acted paternalistically on behalf of their patients. Contemporary health care ethics contend that physicians should not take on this role alone. Particularly in light of health care moving to team consultation, physicians do not know what their intact patients want done in the event of serious illness.[61] Additionally, physicians typically underestimate their patients' quality-of-life and are thereby less likely to favor life-sustaining treatments than are the patients themselves.[62] A surrogate serves as the patient's representative; ideally the patient should make this choice when they are able to make an informed decision. Often next of kin serve this role in the absence of a formally designated surrogate.[63] The surrogate is expected to make health care decisions based upon substituted judgment; making decisions based upon what the patient would have wanted if they had decisional capacity.[64] Many maintain that the

incapacitated patients' family is the most appropriate surrogate decision-maker but empirical studies suggests that nuclear family members generally do not know the preference of patients regarding the termination of life-sustaining treatments and thus would not reach the same decisions that the patient would have reached.[65] Studies have found that shared decision-making about end-of-life treatment choices has been often incomplete, especially among less educated families. But what was noted was the higher levels of shared decision-making were associated with greater family satisfaction.[66] In the interest of justice and dignity, the families members making certain medical decisions must ensure that the patients', not the decision-makers, needs are most important in determining decisions.[67] Additionally, one third of surrogates had a significant prolonged negative psychological experience after making an end-of-life decision for a family member. A small number had a positive emotional response when they were confident they knew which treatment the patient would have wanted.[68]

Naming and Advising.

In light of these findings, naming and advising a surrogate decision-maker is extremely critical in making the patients' wishes known. Surrogates often have to play a role in decision-making even when the patient is not at the end-of-life.[69] The important considerations in naming a surrogate decision-maker are someone you trust, someone who knows you well, and will honor your wishes. Often people assume their closest relatives would be the ones who would know their wishes the best. However, people often find when actually talking to their loved ones about situations needing a surrogate decision-maker their views is very different. The key to assuring that your surrogate decision-maker knows what one would want is talking openly about one's preferences.[70]

Sharing your personal concerns, values, your spiritual beliefs, and about what life worth living would look like then share that with your surrogate decision-maker. To alleviate any disagreement and to ensure that one's wishes are followed, one must communicate with family that you have knowingly shared your desires with your surrogate decision-maker and would ask them to abdicate totally to your decision-maker and your wishes.[71] Some of the most difficult problems in contemporary health care ethics are in the area of decision-making for patients who no longer have capacity to make their own decisions. The main issue is on what moral grounds such decisions ought to be made. Respect for the non-autonomous patients' autonomy should be the guiding norm for the surrogate decision-making. Thus, the surrogate in making health care decisions should use the substituted judgment standard. This will be possible because of the information shared with the surrogate decision-maker by the patient prior to incapacity.[72]

3. Conscience Clause.

Furthermore, professional responsibility typically involves the need for a conscience clause to protect clinicians. Three topics shed light on the conscience clause: the historical perspective, consent paradigms and physician perspectives.

Historical Perspective.

Because of the tidal wave in the patient autonomy movement that has been gaining momentum for decades, the physician is sometimes viewed as only the patient's agent. Because of advertising, Internet and peers, the physician has just become the patient's technical accomplice. Sometimes the physician has had to abandon their own moral agency in order to fill the role that the patient desires, thus threatening the autonomy of the physicians.[73]

With the advent of secularism and the effects of patient autonomy, many physicians, ones with moral conviction or religious beliefs, feel marginalized. A need for statutory protection for these physicians arose. Congress has passed the Church Amendment to specifically address abortions and forty-six states followed suit. This amendment protects physicians from consequences for their refusal to participate in abortions. Some states expanded this law to cover other morally objectionable services such as contraception, sterilization assisted reproduction, human cloning, physician-assisted suicide, fetal experimentation, and withholding or withdrawing life-sustaining treatments. Laws have gone even further to cover other health care providers such as nurses and pharmacists, as well as the health care institutions, hospitals and insurers. This legislation is still in effect today and is called the 'conscience clause.'[74] These conscience clause laws have given significant protection to physicians. Patients are unlikely to have any remedy against the physician that refuses to give medical services because of their personal moral objections. It can be argued that these clauses allow physicians to refuse too many situations without concern for the patient's ability to acquire these medical services.[75]

The real issue with conscience clause legislation results in too many situations where physicians arbitrarily refuse medical services to patients and, therefore, restrict the patient's ability to access much needed medical care. The current conscience clause policy strikes the wrong balance between patient access to medical services and the physician's ability to refuse to offer services for many patients; thus, needed medical services are denied.[76] Furthermore, state boards have the authority to regulate the medical profession. Conscience clauses for physicians limit many state licensing boards from

discriminating against conscientious refuters. Without these laws stated as a conscious clause, the licensing boards could have freer rein on constraining physician's conscience. A physician's refusal to provide morally objectionable service might be construed as unprofessional.[77] The concept of professionalism plays a significant part of this conscious clause debate. At the heart is the question: whether or not a professional is always willing to place the needs of others before themselves. Often professional organizations disagree as to the correct model for doctor-patient relationships and to what specifically the physician owes the patient.[78] One such organization is the American Medical Association. Its code of medical ethics states that physicians have a responsibility to place "the patient's welfare" above their own while allowing physicians, beyond emergency circumstances, the discretion to refuse to provide medical services. Moreover, professionalism does not require a physician to completely subordinate his own personal interest in lieu of those of the patient; this standard is known as the 'primary principle.'[79]

Historical developments have changed the concept of what it means to be a physician and even sparking the controversy of the conscience clause itself, beginning with the emergence of a consumer-based medical system. A change in the paternalistic role of the physician toward the patient autonomous model has eroded the professional stature of the physician. The relationship between physician and patient has become one of a contract.[80] Likewise technological developments, particularly at the beginning and end-of-life, have had a tremendous impact on what it means to be a "good doctor" and raise many issues about what is his true duty. Finally, the physician may no longer be willing to totally pay the price to be the "professional" that has permeated the definition

of a professional physician. Instead the physician may be looking to have significant balance in his life and not totally sacrifice himself for his patients.[81]

The use of the conscience clause may allow a physician to use it inappropriately, thus calling into the question one's professionalism. Different paradigm models have emerged that may give insight into answering this question: What is a professional? Paradigms to be discussed include the models of consent, patient-centered, physician-centric, and gatekeeper.

Consent Paradigm.

In the consent model, both a physician and his professional obligations are voluntary. This model recognizes that certain physical risks involved in the profession exist. By becoming a physician, voluntarily one has acquiesced to these risks.[82] A physician has to accept a set of obligations that are "all-or–nothing" when it comes to selecting personal obligations and potentially rejecting others. The services that a physician provides is determined by what is socially acceptable of a "good" physician, not by an individual physician. Right and wrong are not determined by the norms of the physician.[83]

In the patient-centric model, the physician has to provide all medical services within his specialty. One should not be a doctor if he has moral conflicts. The physician should provide any appropriate medical care as long as it is legal and desired by the patient. This is a model for the "technician," where there is no room for personal morality or personal autonomy.[84] In the physician-centric model, the physician has an inalienable right to conscientiously object on moral grounds not to provide services he deems morally offensive. In this model, a physician does not have to sacrifice his freedom just

because he chose to be a physician.[85] The gatekeeper model contends that the physician has a duty to provide service when he has a special ability and when others rely on this specialty of medicine. In this model it has been suggested that there could be 'just' distribution of medical services without impacting the autonomy of the physician. One of the physician's obligations would be to prevent their conscientious refusal from becoming a burden to patient access.[86]

Physician Perspective.

The balancing act continues between supply of physicians and patients needing medical services that may be deemed morally objectionable. It would become a professional obligation for a physician, who refuses medical services because of their moral conviction, to register with their licensing board. A licensing board would be responsible for determining if the physician is sincere in invoking the conscience clause. The licensing board would test both the validity and sincerity of the physician's beliefs, thus alleviating potential conflict. A registration system would be a simple means of measuring supply of physicians as well.[87] If there were a sufficient supply of physicians willing to provide potentially morally objectionable medical services to a potential population, there would be no imbalance. An outcry to question the conscience clause would no longer be necessary. Still remaining is the question of imbalance. If the balance were deemed a reality, then licensing boards could be required to be engaged in helping to assess the patient demand for medical services. Licensing boards could glean this information from various sources such as insurance companies and hospitals that routinely collect such data.[88]

Informed consent, which has developed only in the last 40 years, is a result of a shift from paternalism to patient autonomy. Informed consent is a doctor's obligation. The physician has an ethical responsibility to disclose all reasonable treatment options even those that the physician does not provide. The responsibility to disclose options extends to the physician who refuses to perform a particular medical procedure even if one finds it morally repugnant. Their duty is not unlimited. The physician must provide all the facts to allow a reasonable patient to make an appropriate decision.[89] Physicians cannot discriminate against patients based on patient characteristics; they must fulfill their obligation to notify patients about services not performed based on moral grounds. The physician must offer information regarding medical options even if the patient's physician does not offer that service. In an emergency, the physician must provide for patient to the best of their ability. Some suggest that the physician must be required to refer to someone who can provide the needed medical services. Furthermore, physicians should not abuse their power when giving advice as to the patient's best course of treatment.[90]

Patients also have a responsibility to show respect and consideration for the autonomy of the physician. Both sides of the physician-patient relationship have rights and obligations. It is in the best interest of the patient to glean, as early as possible, the physician's moral beliefs to foster a better doctor-patient matching to avoid conflicts.[91]

The issue of referral is one of the most difficult aspects of the conscience clause debate. Much conversation has circulated around a physician who morally refuses to provide medical services. The physician should be required to offer a patient a referral to a physician who will provide that service. Problems arise for many reasons but most

notably that the physician could view this as participating in formal cooperation. A potential remedy could be for the refusing physician to provide a list of cooperating physicians. This too has questions of moral complicity and the culpability. At the very least a physician could refer the patient to a state licensing board to secure a potential physician who would provide the medical services requested.[92]

In cases of emergencies, the medical institution has a legal obligation under the Emergency Medical Treatment and Active Labor Act to stabilize the patients presenting themselves with a medical condition without regard to their being unfunded. Emergency Medical Treatment and Active Labor Act does not preempt the conscience clause in protecting individual physicians. In an emergency situation, a physician may have a moral issue but is able to pass the patient to another physician who is more morally in-line without imposing risk to the patient. The major concern is where a transfer is not possible; in this case, the patient could be seriously wronged and/or harmed.[93] Another emergency might occur when a patient lacks access to services within a specific geographic area deemed deficient in those medical services; such areas could be defined as an emergency situation and require the physician to treat it as an emergency. This declaration of an emergency could be made by the state licensing board.[94]

II. Practical Ethical Principles for Catholic Health Care.

The above basic concepts of social, pastoral, and professional responsibility led the *Ethical and Religious Directives for Catholic Health Care Services* to develop practical ethical principles for Catholic health care. These principles are based on the premise that man is not the master of his life; God is and has dominion over it.[95] The duty to preserve our life and use it for God's glory is a positive precept but it is not absolute.[96]

The practical ethical principles in the Ethical and Religious Directives address the following: the distinction between ordinary and extraordinary means of treatment; the principle of double effect; and the principle of cooperation. These are discussed in turn.

A. Ordinary and Extraordinary Means.

In the Catholic moral tradition a balance of proportionality has to be achieved. To that end an historical survey and decision-making foundations will be discussed with regard to ordinary and extraordinary means. There will be an accompanying analysis and appropriate discussion in referencing applicable Ethical and Religious Directives.

1. Historical Survey.

In the section, a discussion of early moral theologians and subjectivism and relativism will ensue.

In the tradition of the Catholic Church it is held that man is not the master of his own life. God is the master and has dominion over it. Human life is a gift from God.[97] Since man does not have absolute authority over life one can conclude that we do have an obligation to take care of it.[98] This point is indicated in the Ethical and Religious Directives in this manner: "We are not owners of our lives."[99] Therefore, we do not have life and death decision-making authority when it comes to the final disposition of our lives. God has given us the gift of life, not as a right that we can claim but a gift that we may receive.[100] We are more life's administrator.[101] The duty to conserve our lives is one side of the moral coin while the prohibition of suicide is on the other.[102] This point is mentioned in the Ethical and Religious Directives in this manner: "We have a duty to preserve our life and use it for the glory of God."[103] God's attitude towards us is marked by generosity, faithfulness, and grace. We must extend those similar qualities to others.

Having received so much from God's bountiful care, we can give to others gratitude of our hearts and this is what gives glory to God.[104] This duty to preserve our lives is a positive precept but it is not absolute. The significance is described in Ethical and Religious Directives in this manner: "We do not have absolute power over life."[105] Life has infinite value and lived well leads to gratitude, wisdom, and sanctity. We must realize that we are sent to fulfill a God-given task.[106]

This begs the question, "When is it enough?" raising the core distinction of extraordinary means versus ordinary means in preserving our lives.[107] The distinction is expressed in the Ethical and Religious Directives in this manner: "A person has a moral obligation to use ordinary or proportionate means of preserving his or her life. Proportionate means are those that in the judgment of the patient offer a reasonable hope of benefit and do not entail excessive burden or impose excessive expense on the family or the community."[108] Often at the beginning of a serious illness many medical interventions seem appropriate but there usually comes a time when continued treatments are no longer a benefit to the patient. This is not abandoning the hope of cure rather acknowledgment of the human condition and the limits of medicine.[109]

Early Moral Theologians.

Historically, the seed of this distinction can be traced back to St. Thomas Aquinas (1274 d.). Although he did not specifically develop this concept regarding the duty to preserve life, he recognized that it does have limits. This point is explained in the Ethical and Religious Directives in this manner: "no person should be obliged to submit to a health care procedure that the person has judged, with a free and informed conscience, not to provide a reasonable hope of benefit."[110] In Catholic moral tradition, simply

prolonging physical life, especially when that means precarious and burdensome, is not a requirement. The "hope of success" is best used in thinking of assessment of any medical procedure.[111] Later theologian, Francisco de Victoria (1545 d.) clarified that it is one thing not to protect life and it is another to destroy it. He expounds by saying that one is not obligated to expensive or extravagant cures or the best food or the healthiest air. Victoria says the obligation to conserve our life does not bind us when food or medicine exceeds what is customary, even if death is probable.[112] This point can be explained using the Ethical and Religious Directives in this way. Excessive burden is not required to prolong life if determined by a free and informed conscience. The conscience, the "most secret core and sanctuary" where one is alone with God to help make judgments about what one ought to do or not do. To aid in that conscience formation, one must search for truth, discern what is right and good, and then act accordingly.[113]

Dominic Soto (1560 d.) makes a similar point about the preservation of life due to an infected leg and subsequent amputation. Dominic Baenz (1604 d.) is the first to contrast ordinary means and extraordinary means. This point can be explained using the Ethical and Religious Directives in this fashion. A free and informed conscience by the patient is required to determine what is proportionate and what is excessive. Making such decisions in the Catholic moral tradition is the right of the patient or their surrogate. Such decisions should not be taken lightly and should be made taking into consideration Catholic moral teachings.[114]

With the rapid advancement of medical technology in the 20th century, Catholic theologians were forced to clarify the view of sanctity of life and the enormous costs associated with adhering to that concept.[115] This subsequently led to the Church's

response in 1957 with Pope Pius XII's (1958 d.) declaration that normally one is required to use only ordinary means.[116] The essence of this response in the Ethical and Religious Directives is posited in this way: "Disproportionate means are those that in the patient's judgment do not offer a reasonable hope of benefit and or entail an excessive burden, or impose excessive expense on the family or the community then there is no requirement to use extraordinary means to preserve life."[117] Medical interventions that seem no longer to correspond to the real situation of the patient may be discontinued. That real situation can involve disproportionate means or an imposition of an excessive burden. The Catholic moral tradition has been very willing to acquiesce to the free and informed conscience of the patient.[118]

Subjectivism and Vitalism.

This declaration of Pope Pius XII (1958 d.) aligned the issue of ordinary/extraordinary means with the distinction between subjectivism and vitalism. The two key principles of medical ethics for assessing this are beneficence and non-malfeasance. Subjectivism maintains that one's primary obligation is to oneself, human life having no intrinsic value and life only having value if an individual gives it such. Fundamentally, the dignity of life is rejected because life only has worth and value if an individual sees life as valuable.[119] Vitalism claims that life itself must be sustained at all cost because of its greatest possible value. Vitalism forbids discontinuation of efforts to prolong life.[120]

2. Decision-making Foundations.

The defining of elements and making a moral assessment will be discussed as it relates to ordinary/extraordinary means.

Defining Elements.

To bring the argument back to ordinary/extraordinary means requires a set of criteria for making important distinctions. On the one hand, ordinary means has four major elements: (1) Reasonable hope of benefit: this benefit must have both quality and duration. If something offers little benefit then it would be unreasonable for someone to be morally obligated. (2) Common means: one does not have to go beyond what would be common diligence. To go beyond the usual would increase the extraordinary nature. (3) Proportionate according to status: it must be reasonable according to one's financial or social status. (4) Undemanding means: the balance must be struck between gravity of the moral law and the recognition that the obligation is too difficult to fulfill. The excessive difficulty is the key not the ordinary means being free of any difficulty.[121] In the *Ethical and Religious Directives for Catholic Health Care Services*, the obligation to submit to a health care procedure can only be judged by a "free and informed conscience." The Catholic moral tradition does not address specific technological remedies or interventions but asks whether a medical treatment is burdensome or beneficial to the patient.[122]

On the other hand, there are four aspects in helping to determine extraordinary means: (1) Great effort: exerting tremendous amount of effort is not required. (2) Enormous pain: an unreasonable amount of pain can be recognized as extraordinary. (3) Extraordinary means and expense: an obligation to spend an exorbitant amount of money to conserve life is not mandatory. A person may decide not to impose excessive cost to oneself, one's family, or the community. (4) Severe dread: an intense fear or abhorrence toward a means can be viewed as extraordinary.[123] A strong repugnance can also make an

ordinary means excessively burdensome.[124] In the Ethical and Religious Directives, all four of these aspects presented help clarify what would be excessive and burdensome judged by a "free and informed conscience" of the patient.[125]

Moral Assessment.

A moral assessment of each individual case must come before it can be decided whether a particular treatment is ordinary or extraordinary. The definition of ordinary means is usual, commonplace, not exceptional and conversely extraordinary means unusual, uncommon, and exceptional.[126] All these definitions could be rejected for terms such as ethically indicated or non-indicated, which substantially make the distinctions more understandable. The distinction between ordinary means and extraordinary means can be very deceptive because of their appearance of simplicity.[127] To clarify these terms, the distinguishing aspect of ordinary from extraordinary in Catholic moral theology is whether the treatment is beneficial (ordinary) or excessively burdensome (extraordinary).[128] The criteria for decision-making need to relate primarily to the patient not the remedy.[129] The specific criteria which can relate to risks, costs, pain and likelihood of success, anticipated results and side effects can reduce confusion but also provide an opportunity to discuss complex issues among all stakeholders.[130] In the Ethical and Religious Directives, the decision-making revolves around the judgment of the patient not the treatment. The health care team and other stakeholders often overlook this as well.[131]

B. The Principle of Double Effect.

The second focus of practical principles in the Ethical and Religious Directives deals with the principle of double effect. Here the distinction between ordinary and

extraordinary means is applied to provide practical distinctions to resolve moral dilemmas. To discuss the principle of double effect it is helpful to look at its historical perspective before considering its implementation.

1. Historical Overview.

Formulation of the principle of double effect and an articulation of the debate-shaping standard will ensue.

Formulation of Principle

Historically, since the time of St. Thomas Aquinas, Catholic medical ethics has utilized the principle of double effect. The principle of double effect is still widely utilized in Catholic bioethics today.[132] It is thought that St. Thomas Aquinas (1274 d.) was the first to formulate the principle. Some argue that the principle originates much earlier in implicit moral reasoning even dating back to the Old Testament. There are examples of a justifiable act that causes both good and bad effects in early Scripture. These justifiable acts utilized moral reasoning, very similar to the principle of double effect.[133] Aquinas was first to analyze a case of self-defense from which two effects, one good and one bad, would occur. Aquinas utilized this principle in the situation of self-defense against an unjust aggressor. In developing the first nascent version of the principle, the concepts of dual effects, intentions, and proportionality were utilized. Clarity and attention to the principle of double effect did not occur until two centuries after Aquinas. Cardinal Cajetan (1534 d.) clarified the principle's effectiveness.[134] It was not until the publishing of Jean-Pierre Gury's (1866 d.) work in 1866 that awareness was brought to the principle as a normative tool for all of moral theology.[135] In the 20th century, the Ethical and Religious Directives applied to principle to various dilemmas

regarding death, emphasizing the following: the dignity of the patient as they approach death is what is paramount.[136] This point is explained in the Ethical and Religious Directives in this manner: "Medicines capable of alleviating or suppressing pain may be given to a dying person even if this therapy may indirectly shorten the person's life so long as the intent in not to hasten death."[137]

Debate Shaping Standard.

In St. Thomas' general statement about the application of the principle of the lawfulness of killing in self-defense, an act can have two effects. We understand it today as an articulation of the principle of double effect. One of the effects is intended while the other is unintended.[138] Even though one of the effects is bad but not intended then the act itself can be licit. This occurs because the character of moral action derives from what is intended, not from what is outside of that intention. But if there are two effects, one good and one bad, even if only the good effect was intended we cannot always conclude the act is licit.[139] St. Thomas says, "An act that proceeds from a good intention may be rendered illicit, if it is not proportioned to the end intended."[140] Thus, it is imperative to analyze the action and its effects to determine its lawfulness. This was purported to be the only time Aquinas directly addressed the principle of double effect.

After the contributions of Aquinas and others as mentioned earlier, the principle reached a level of consistency in understanding and use with the work of Jean Pierre Gury (1866 d.). It was Gury's work that produced the distinct conditions that exists today.[141] The principle was further developed by Peter Knauer (1935 b.) in the 20th century that led to the establishment of the following conditions of principle of double effect.[142]

2. Implementing the Principle of Double Effect.

Conditions that are applied to implementing the principle of double effect and the application of the principle will be discussed.

Conditions.

To justify an action that may cause a bad effect, in addition to caused good effects, the principle of double effect to be correctly applied has four main conditions that must be satisfied. To apply the principle to an action, the conditions are listed in a logical order. While the first two conditions deal with the act itself, the latter two deal with intentionality and the consequences.[143] The four conditions of the principle of double effect are as follows:

1. The action and its effects, considered by itself must not be morally evil.
2. The good effect must not be caused by the bad effect.
3. There must be no intention of the bad effect.
4. The good effect must outweigh the bad effect.[144]

These four conditions give us a template to normatively judge good and evil consequences. Being an effective normative tool, the principle of double effect can aid us in morally distinguishing various ethical decision-making options.[145] At the end of the 20th century, the United States bioethicist David Kelly argued for a further refinement of these conditions. He argued that the third condition should be "intend as an end to be sought" and not "intend either as a means or as an end" as is typically understood.[146] He argued that in foregoing life-sustaining treatment, the justification for doing so in the Catholic Tradition sheds light on the conditions of the principle of double effect. He insisted that the third condition of the principle of double effect is reduced to a form of

the first two principles of double effect conditions.[147] His point was to focus upon the distinction between morally intended action and the unintended side effects.[148] The contributions of Knauer and Kelly continue to shape the development of the principle of double effect.

One final point needs to be made about using the conditions of the principle of double effect, the use of the terms "direct" and "indirect."[149] These terms are utilized to apply to actions after they have gone through the scrutiny of the four conditions of the principle of double effect. If an action meets all four conditions, then it is considered "indirect" and acceptable. If they do not meet the four conditions then they are "direct" and are considered forbidden.[150]

Application.

The application of the principle of double effect is commonplace. However, using the principle of double effect to make the distinction between killing and allowing to die can be one of the most heart-wrenching in medical care. It is sometimes moral to allow a person to die but the direct killing is never morally correct.[151] The withholding of life-sustaining treatment is an example of allowing to die. The Ethical and Religious Directives explain this concern in this manner: "The free and informed judgment"[152] of the patient dictates utilization of the withdrawal of life-sustaining procedures if they are not contrary to Catholic moral teaching. While living the many passages of life well, we also should prepare for our final passage to death.[153] This preparation requires us to consider the use of life-sustaining technology.

The use of certain medical means (ventilator, cardio-vascular resuscitation, or pressors, etc.) is not killing the patient but allowing a natural death. If it is "morally

extraordinary," then the decision not to use these means is generally accepted as moral.[154] Withdrawing life-sustaining treatment is another action that requires evaluation as to its acceptability. The action of withdrawing life-sustaining treatment would be considered equal to withholding life-sustaining treatments in the Catholic moral tradition. This would be contingent upon the assumption that the burden outweighs the benefit. The Ethical and Religious Directives describe this situation in this way: "The person has a moral obligation to use ordinary or proportionate means of preserving his or her life. Proportionate means are those that in the judgment of the patient offer reasonable hope of benefit and do not entail an excessive burden or impose excessive expense on the family or community."[155]

By embracing the reality of our mortal life, we anticipate eternal life.[156] Withholding and withdrawing treatment may seem vastly different but morally there is no difference.[157] This point is explained in the Ethical and Religious Directives in this manner: "A person may forgo extraordinary or disproportionate means preserving life. Disproportionate means are those that in the patient's judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community."[158] Only by facing our mortality can we anticipate the life that transcends death. This vision of a perfect life, God has promised us.[159]

Another action that has traditionally been accepted as ethically justifiable by the principle of double effect is that of palliative sedation. The Ethical and Religious Directives elucidate this situation in this manner: "Patients should be kept as free of pain as possible so that they may die comfortably and with dignity, and in the place where they wish to die."[160] Care is certainly something other than cure. Cure can become

violent, manipulative, and even destructive if it does not grow out of care. Care is being with, suffering with, and feeling with another. Care is compassion. We may not always be able to cure, but we are always able to care.[161] When patients are experiencing intractable pain at the end-of-life, extreme measures to gain control of that pain may have to be utilized. One of those extreme measures is that of sedation. This concern is addressed in the Ethical and Religious Directives in this way: "Medicines capable of alleviating or suppressing pain may be given to a dying person if this therapy may indirectly shorten the person's life as long as the intent is not to hasten death."[162] Intentionality has to be tempered with the knowledge of proportionality.[163]

Palliative sedation potentially can cause the patient to lose consciousness to adequately relieve the refractory symptoms. With the goal to eliminate pain, suppression of respiration may be the cause of their death. Relieving pain is certainly a moral act. Therefore appropriate palliative medication to relieve intractable pain at the end-of-life can be considered ethically justifiable.[164] This point is explained in the Ethical and Religious Directives in this manner: "One of the primary purposes of medicine in caring for the dying is the relief of pain and the suffering caused by it."[165] But what must be kept in mind is that often the greatest suffering is loneliness, the feeling of being unloved and unwanted. Supportive presence may be the most appropriate gift that one can give to the dying.[166]

Euthanasia and physician-assisted suicide cannot be justified by principle of double effect. This point is emphasized in the Ethical and Religious Directives in this manner: "Catholic health care cannot condone or participate in euthanasia or physician assisted suicide."[167] We must live in response to God and face life's challenges and

difficulties in hope. Our challenge and goal is to share that with those who are struggling and discouraged.[168] The very act of purposefully ending life is morally evil and so is prohibited by the first condition of the principle of double effect; the act cannot be morally evil. The evil act must not produce a good effect is the second condition. It is not fulfilled because the evil effect, the death of the patient, is the means of producing the good effect, the relief of the patient's suffering. The first two conditions of principle of double effect are intended to alleviate any rationalizations of evil actions.[169] These are applications that are readily addressed but there are many other applications of principle of double effect, as one of the most useful normative tools of Catholic moral theology.[170]

C. Principle of Cooperation and Complicity.

The third focus of practical principles in the Ethical and Religious Directives deals with the principle of cooperation to address issues of complicity. The principle of cooperation was developed to analyze a person's moral action and to help determine whether one's action contributes to the wrongdoing of another.[171] Again, a historical perspective clarifies basic distinctions in the principle.

1. Historical Overview.

In providing a historical overview, the original purpose as well as a discussion of its theological development will ensue.

Purpose.

The principle of cooperation, a principle of Catholic moral theology, was developed to analyze a person's moral action. This theological principle also helps determine whether ones action contributes to the wrongdoing of another.[172] The principle of cooperation came about because of the concern that there are times when bringing

about good is almost impossible without associating with others wrongdoing.[173] The Ethical and Religious Directives explain "activities must be limited to what is in accord with the moral principles governing cooperation."[174] Cooperation is relevant for us because of being called to be disciples to advance the kingdom of God. Because of our identity and integrity, the principle of cooperation helps us to be who we claim to be and act accordingly.[175]

"Cooperation" has a positive connotation in English usage. It connotes the working together for common good. In the case of this principle, it involves one's action and has been expanded to include the actions of an institutions as well as an individual. The message of the Ethical and Religious Directives is thus: "Catholic partners should avoid entering into partnerships that would involve them in cooperation with the wrongdoing of other providers."[176] The principle of cooperation has become a useful tool for today's health care environment by guiding us as we advance the kingdom of God.[177] The principle was originally formulated to help individuals and their confessor determine if and how they might act morally when they come in contact with the actions of others who were involved in wrongdoing. In the context of the practice of the Catholic sacrament of Reconciliation, guidance was needed to aid the penitent and confessor.[178]

Theological Development.

Historically, St. Thomas Aquinas (1274 d.) was one of the first theologians to give some direction regarding this principle when his observations later became known as the principle of double effect.[179] In the 16th century moral theologian, Thomas Sanchez (1610 d.) articulated a concern about individuals cooperating directly with evil.[180] St. Alphonse Liguori (1787 d.) gave the principle of cooperation much of its present form.

The principle of cooperation can be seen as an application of the principle of double effect.[181] In this case, the principle deals with the action of individuals and organizations involved with immoral actions of others.[182] However, some scholars consider the principle of cooperation as distinct from the principle of double effect. The reason is because cooperation involves two agents with distinct moral actions, whereas double effect involves a single moral agent with good and bad effects related to action.[183] However, the principle of cooperation is quite different from the principle of toleration. The principle of toleration, advanced from the time of St. Augustine, deals more with the power of institution that has the wherewithal to overcome evil but chooses to tolerate the immoral action for the greater good.[184] Pope John Paul II (2005 d.) in his 1995 encyclical, *Evangelium vitae*, acknowledged the principle of toleration explaining that "public authority can sometimes choose not to put a stop to something which were prohibited would cause more harm" (no. 71).[185]

2. Distinctions.

Addressed by the principle of cooperation are actions that are wrong in all circumstances (intrinsically evil) and to justify cooperation, the action of the person cooperating cannot be wrong. In avoiding moral culpability, the distinction between illicit formal and licit material cooperation must be made.[186]

Formal Cooperation.

If one were to knowingly and willingly cooperate with someone who performs evil acts or were to withhold actions that would prevent such acts, this would be considered morally wrong. This point is explained in the *Ethical and Religious Directives for Catholic Health Care Services* in this manner: "Catholic health care organizations are

not permitted to engage in immediate material cooperation in actions that are intrinsically immoral."[187] To maintain an individual and/or institutional identity and integrity, asking these questions should precede every act of permissible cooperation: How will cooperation likely affect one's identity and integrity in this instance? How will this action impact others? Does this action advance the kingdom of God?[188] Additionally, to encourage another to perform acts of evil or to agree with the evil purpose, even if no physical action were extended, is also morally wrong. To directly intend the evil act is to share in moral responsibility.[189]

The critical factor is intentionality or voluntariness.[190] When a person cooperates, clearly intending the wrongdoing, the formal cooperation would be explicit. If cooperation were not explicit but nonetheless immediately associated with wrongdoing, this category would be implicit formal cooperation. To clarify, explicit is when there is clear intention in the wrongdoing, therefore wrong. Implicit formal cooperation is when there is actual cooperation in the wrongdoing.[191] When cooperation is utilized to justify a cooperating action, that action is mediate material cooperation.[192] In assessing formal cooperation, one must assess the intention of the cooperating agent. Two questions must be asked: (1) is the cooperating agent contributing to the morally wrong action in an essential way? (2) is the cooperating agent in agreement with the morally wrong action? If the answer is yes to both then this is explicit formal cooperation and illicit. If the first answer is yes and to the second question, no, then the question has to be answered: is the cooperating agent participating in the action in such a way as to assume that the cooperating agent agrees with the morally wrong action? If yes, then this is implicit formal cooperation and also not acceptable.[193] The Ethical and Religious Directives

explain that limitations must be placed on the participation in activities that would be judged morally wrong by the Church. To apply the principle of cooperation, particular arrangements have to be considered such as ownership, governance, management, finances, actual performances of the deed, and scandal. Because of our call to be a prophetic witness it may be necessary to cooperate in order to achieve some good and/or avoid some harm.[194]

Material Cooperation.

With material cooperation, in some way one is involved with the wrongdoer but does not share in the intentionality. In this case one should not participate in the illicit act of another person and ought to be only involved with the acts that either proceed or follow the wrongful act.[195] Mediate material cooperation involves a cooperator only with action and not with the will of the person doing the wrong. The wrong action is neither approved nor desired by the cooperator, thus the cooperator is unwillingly involved.[196] Prudence must guide those involved in regards to questions of intention, duress, distance, necessity, and gravity.

To assess material cooperation there must be no intention or agreement of the cooperating agent with the action. The cooperating agent still in some way contributes to or facilitates the wrongdoing. The question that has to be asked in this case: is the action of the cooperating agent performing good or at least morally indifferent action? Additionally, does the cooperating agent contribute in a substantial way, providing an essential element, without which the act would not be accomplished? If the answer to this question is yes, the action is immediate material cooperation and usually not acceptable. If the answer is no, the subsequent question has to be asked: does the cooperating agent's

action contribute some non-essential element? If the answer is yes, the action is mediate material cooperation and can be morally permissible. In the utilizing the principle of cooperation, the Catholic Church demonstrates the rejection of relativism as well as the avoidance of the moralistic hyper-rigorous tradition that would reject any collaborative efforts with those that the Church may have value disagreements.[197]

However, the use of the principle of cooperation requires that scandal be avoided.[198] To use material cooperation, the possibility of scandal must be eliminated.[199] The *Ethical and Religious Directives for Catholic Health Care Services* explain as follows: "The possibility of scandal must be considered when applying the principle governing cooperation."[200] Scandal in this environment is not what might be newsworthy but what may lead one to sin. Scandal is morally offensive to others, may incite others to do evil, or might provide others with an occasion for morally wrongful conduct. How we act or do not act may appear to encourage the virtuous conduct of others. The appearance of scandal amounts to doing wrong against our neighbor; because love of our neighbor dictates that we encourage one another to virtuous conduct.[201]

III. Conclusion.

The practical ethical principles of Catholic health care including ordinary and extraordinary means, double effect, cooperation, and complicity give us basic principles to better implement the *Ethical and Religious Directives for Catholic Health Care Services*. This provides a normative framework for Catholic health care ethics, creating a foundation for the ethical decision-making models to be dealt with in the following chapter.

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Chapter 3. Ethical Decision-Making Models Consistent with Catholic Ethics.

To discuss ethical decision-making models consistent with Catholic ethics requires examining three related topics: moral agency and organizational ethics, the competence of patients for making end-of-life decisions, and the role of clinical ethics consultation services.

I. Organization Ethics and Moral Agency.

Moral agency is the state by which organizations, as well as individuals, are held accountable for making right or wrong decisions. Both organizations and individuals are expected to act ethically in all matters and to be evaluated accordingly. While most Health Care Organizations have ethics committees to assist in establishing and maintaining standards, often those committees are insufficient and cannot carry this burden alone. All members of the Health Care Organizations must be responsible for the organization's understanding of moral agency, and all employees must manifest this understanding as they perform their assigned duties. Health Care Organization are ethically responsible yet are constantly being challenged by both internal and external stakeholders. This chapter will discuss common dilemmas that must be addressed by Health Care Organizations to meet expected ethical standards in clinical, professional, and organizational environments.

A. Characteristics.

First, the characteristics of organizational moral agency engage two foundational issues: the purpose of moral agency and the role of ethics in the organization. Organizations like individuals have moral agency, but in different ways. They both have purpose that must be evaluated in terms of being accountable through conscience.

Organizational moral agency, as well as clinical and organizational ethics, has distinctiveness in healthcare ethics that will be discussed.

1. Organizational Moral Agency.

To evaluate Organization Moral Agency, the ethical aims have to be identified and ethical accountability has to be established.

Ethical Aims.

Organizations have moral agency because they have a defined purpose. Individuals have a purpose and, if not fulfilled, will also be subject to the whims of the universe. This purpose of organizations, like individuals, involves ethical aims. To pursue these ethical aims, organizations set goals. In this goal setting, manifested as mission statements, strategic plans, and budgets, organizations act like individuals insofar as they pursue moral agency. This moral agency means they have responsibilities to society, to other institutions, to other individuals within and without the organization, and ultimately to the people they serve.[1]

Ethical Accountability.

Another aspect of moral agency is that organizations will periodically be evaluated. This evaluation will occur internally as well as externally to monitor their activities with regard to their ethical aims. Individuals they come in contact with, society at large, as well as the recipients of their service measures this evaluation. Part of that evaluation will be to determine whether they have been socially responsible, how they treat their employees and individuals, and most especially how they have fulfilled goals stated in their mission statement. Such evaluation highlights the ethical accountability of organizations. Organizations are held morally accountable insofar as they are systems

with ethical aims (goals, mission statements, etc.) that are evaluated. Here the difference between organizational and individual moral agency becomes apparent. Individuals and groups act as moral agents with ethical aims and accountability, whereas organizations act as moral agents with ethical aims and accountability by analogy. That is, organizations are not human individuals; but their ethical aims and accountability are similar to that of human individuals. Hence, organizations have moral agency by analogy to individual moral agency.[2] Just as individuals are responsible for their formation of conscience, organizations are responsible for creating that climate and evaluating whether an act fits that climate.[3]

2. Health Care Organizations Ethics.

Within a Health Care Organizations, clinical ethics and organizational ethics need to be discussed in a related manner.

Clinical Ethics.

Often clinical ethics have organizational ramifications. Structural problems in the organization can come to light as clinical cases are reviewed. Such problems could be the result of inadequate staffing, inept administration of medications, or the absence of clear policies.[4] Other clinical problems may materialize because of organizational changes, such as policy or even directional changes of the Health Care Organization itself. The Health Care Organization may have an impact on the clinical environment if they do not give appropriate ethical consideration to their decisions. Problems can occur if the Health Care Organization is not committed to an integration of ethics throughout the organization. The organization can be accused of not meeting the "moral minimum" or the lack of respect for other stakeholders.[5] Most Health Care Organizations have an

established clinical ethics committee that set guidelines and procedures to address ethical issues occurring in the delivery of health care.[6] Policies are not just theories but practical tools and thus should be implemented with fidelity. Facilitating communications, dispute resolution, and education are just some of the areas in which the ethics committee can aid an organization in adhering to its written policies.

Organizational Ethics.

With the evolution of health care and having a larger stake in society, Health Care Organizations must become more cognizant of their impact and perceptions. Clinical ethics can no longer be confined to case-centered environment but must become part of the organizational culture. Ethical implications must be considered in all their actions. Often they are not addressed by the organization as a whole. The ethical implications are often outside the purview of the ethics committee, yet issues are delegated to that group. Consequently, the Health Care Organization feels they have satisfied their need to consider ethical implications, and no other actions are taken. Areas outside the ethics committee jurisdiction and often overlooked include executive hierarchy, organizational structures, and relations with stakeholders.[7]

Organizational ethics problems can be analogous to individual acts in ethics (i.e. informed consent, choice, appropriate disclosures, etc.) Effective Health Care Organizations ensure protection of their patients in the areas of unauthorized access, patient privacy, patient confidentiality, and safeguards for patient autonomy. In this time of hypersensitivity to access, who has that access and what guidelines are in place to protect the patient's information? These questions and many others point out a significant need for a forum to discuss areas of ethical concern throughout the Health Care

Organization. As moral agents, organizations must pay particular attention to the ethical expectations of society.[8]

B. Ethical Theories and the Ethical Climate in Health Care Organizations.

Second, in addition to the above characteristics, ethical theories impact the health care organization in two ways, relating business ethics with the ethical climate of the organization.

1. Business Ethics and Organizational Ethics.

Stakeholder Theory and Professional Ethics need to be discussed in both business and organizational ethics.

Stakeholder Theory.

Health Care Organizations have unique challenges and obstacles. These obstacles are inherent in an environment that is very competitive resulting in the Health Care Organizations being caught in the tension between profitability and the demand to meet high ethical standards. Therefore, it is necessary to look at various models of business ethics to identify a feasible a model for effective Health Care Organizations.[9] Models such as rational choice theory, integrated social contracts theory, stakeholder theory, and other theories need to be reviewed in light of a Health Care Organization. Each of these theories has their strengths and weaknesses, but stakeholder theory offers the best option for Health Care Organizations. Stakeholder theory is defined as a framework for understanding the potential conflicts of value, loyalty, commitment, and interest of a group of individuals who can be impacted by corporate actions. Stakeholder theory also provides the best integration of financial issues and other considerations, while

recognizing the role of moral agency.[10] Stakeholders have a shared moral community and appeal to fairness principles.[11]

Professional Ethics.

To the naïve, there would seem to be no conflict between organizational ethics and professional ethics; however, an organization must integrate clinical, business, and professional ethics. The latter may be the most important and most controversial. Health care professionals are responsible for patients, to the health care insurers, and to their community. All of these forces challenge the ethics of the individual professional.[12] A professional is defined as exhibiting five attributes: (1) a highly specialized training and role, (2) an interest in society before self-interest, (3) personal self-control ruled by a code of ethics, (4) a desire for rewards as symbols rather than ends, and (5) virtues and morals as guides for ethical behavior. These guiding principles for the professional would be control, responsibility, and virtue. Such guiding principles are the essence of a health care professional whether doctor or nurse.[13]

Professionals, such as physicians, nurses, social workers, chaplains, and therapists have codes of ethics that they all portend to abide by. Governing bodies of Health Care Organizations expect competency and advocacy for patients as a minimal code of ethics. The eradication of conflicts of interest and the elimination of conflicts of commitment, honesty, respect for the law, continuing education in their specialized areas of expertise, as well as a sense of responsibility to society are all attributes Health Care Organization's governing boards expect.[14] Organizational ethics by the Health Care Organizations should be a further attempt to combine all these different codes of ethics into a culture of ethical behavior within a positive ethical climate.[15]

2. Ethical Climate in Health Care Organizations.

Managed care organizations and organization ethics programs will be engaged as they relate to an ethical climate within Health Care Organizations.

Managed Care Organizations.

With the perceived need for health care reform and its failure to come to fruition in 1994, there was a major shift of power from inside the Health Care Organizations to the outside. The power moved to government, both state and federal, and to American business; both are large-scale consumers of health care. This shift was a result of the perceived need voiced by the general population who believed there was "something severely wrong with the health care system."[16] Managed Care Organizations and Health Maintenance Organizations both grew because they were designed to slow health care cost and to provide enhanced health care to a defined group. These types of Health Maintenance Organizations were set up because there was such a tension between profit and service. They were rife with ethical dilemmas. Controlling cost, changing provider behavior, risk shifting, and risk sharing are just some of the potentially ethical problematic areas for Health Maintenance Organizations.[17] To further exacerbate the ethical climate, physicians were subject to new reimbursement schemes, withholds, capitation arrangements, bonuses, and gatekeeper arrangements. Also, physicians were forced to sometimes compromise and balance the tension of good health care and financial reward.[18] Consolidation of Health Maintenance Organizations became the new norm. Consolidation was done to negotiate more clout with all service providers and also to accomplish the economies of scale. Health Maintenance Organization's stakeholders (including patients, physicians, nurses, staff, and the community) can experience

significant angst because of staff reductions and reassignments; another reason to develop desperately needed organizational ethical guidelines that help to create a healthy internal ethical climate.[19]

Organization Ethics Programs.

To achieve a healthy ethical climate requires first looking at a Health Maintenance Organizations relation to its mission and core values to determine if there are any impediments. To help achieve an organizational ethics program, two major stimuli have been instrumental in making Health Maintenance Organizations comply: the first being the Justice Department; and secondly, the standards organization, Joint Commission and Accreditation of Health Organizations.[20] In establishing an effective organizational ethics program, certain criteria must be met: respect, visibility, and proper authority. The ethics program must bring into line mission and codes of ethics that address specific issues such as marketing, admissions, transfer, discharge, billing practices, providers, payers, and educational institutions. Each of these individual issues is required to be evaluated.[21]

The organization's ethics program should be established at the level of Board of Directors and be given responsibility for morale, reputation and the Health Maintenance Organization's competitive advantage. The program should be give decision-making authority but utilized very discriminately. The program should be more than an advisory board.[22] The organization's ethics program should be the umbrella over three subcommittees: the patient care ethics subcommittee, the organization ethics subcommittee, and a professional ethics subcommittee. Each subcommittee should have

its own functions in the areas of education, policy development, consultation activities, and research activities.[23]

II. Clinical Ethics and Competency.

The challenges mentioned above of organizational ethics and moral agency has often led to the compromise of a patient's rights. The Catholic Church asserts patients have a right to make their healthcare decisions.[24] "The decision should be made by the patient if he is competent and able or, if not, by those legally entitled to act for the patient, whose reasonable will and legitimate interest must always be respected."[25] To discuss clinical ethics and competency consists of examining two related topics: competency of the patient and advanced directives.

A. Competency.

First, the fundamental concept in bringing decision-making of the patient to fruition is that of determining competency. Competency engages two foundational issues: decisions by competent patients and decisions for incompetent patients.

1. Decisions by Competent Patients.

Making decisions by competent patients will be engaged from the perspective of paternalism and making treatment decisions.

Paternalism.

Patients that are capable of making decisions about foregoing treatment may refuse that treatment based upon their legal right even against the advice of their physician. The patient has rights of privacy, autonomy, and liberty thus choosing to forgo treatment is within the purview of the competent patient. American law supporting these rights comes from three sources, statutory law; laws passed by legislatures, and

constitutional law. The American Constitution is the source for the right to privacy and autonomy while common-law allows the refusal of unwanted treatments.[26]

Emphasis in modernity has been placed on respecting the patient's autonomy but paternalism continues to occur.[27] Paternalism is when another decides on behalf of the patient; as a result the patient's autonomy is limited. Someone else is making moral choices for the patient about treatment decisions. When competency of a patient is not in question, the patient should be making treatment decisions. The patient knows what burdens they are willing to bear and what risks they are willing to take.[28] Moral responsibility in the case of decision-making continues to fall within the confines of health care professionals. They are the ones responsible for presenting the possible choices to the patient and facilitating the decision-making process.[29]

Another definition of paternalism is when one interferes with the patient's autonomous decision-making to avoid harm and to promote authentic welfare and values of the patient. The physician may feel the expressed preferences of the patient may be inauthentic and therefore may act counter to the preferences of a patient.[30] The physician may feel the patient is not competent or that the patient's decision was coerced. Family members may have appealed to duty or reciprocity and even possibly coercion to solicit compliance with their wishes regarding a particular treatment that is not shared by the patient. An implicit or explicit threat may be influencing the patient. Acting against an inauthentic preference could be defined as "soft paternalism."[31]

Treatment Decisions.

Treatment decisions are not based on knowledge alone but on patient's values and moral beliefs. Values guide a person's behavior and choices while disclosing what offers

meaning and worth. Values are integral to a person and thus often people do not even realize that decisions are based on their values. Because values are unique to each individual they are relevant to decision-making. Decision-making requires value judgments.[32]

Treatment decisions are contextual in nature therefore more than the technical aspects of that decision needs to be considered. Only the patient can know what is most important, requiring their values being considered. Others cannot know a patient's values unless they have shared them. Even with that knowledge making decisions based on other's values is extremely difficult especially if the values are not shared. Consequently, others should not make medical choices for competent individuals.[33]

The knowledge of one's own values empowers the patient to act autonomously. Often patients have not contemplated nor articulated what is most important to them when faced with health care decisions. Health care professionals can and should help individuals clarify their personal values through self-reflection and self-examination.[34] This process includes the clarification phase in which patients select values from among a group of values. Once these values are determined the patient moves on to the prizing phase, a term used to describe values clarification. At the prizing phase, the patient has determined their values and is willing and able to communicate those values to others. The last phase, acting on one's values, allows an individual to make decisions and take appropriate action. The patient is the only one that knows what burdens they are willing to bear therefore treatment decisions are moral decisions belonging to the patient only.[35] One of the most vexing problems for physicians is determining if the patient is capable of making adequate medical decisions. Determination of competency is crucial for

achieving the proper balance between autonomy of the patient and protecting the patient that may have a cognitive impairment.[36]

Competency denotes a legal status that should be determined by a court therefore referring to legal judgments and conversely capacity to clinical ones. These terms are used interchangeably sometimes causing confusion. The physician should continue the tradition of determining patient's capacity and decide when to seek substituted consent. Generally, a medical determination of incapacity is the trigger for activating directives. Consent from an incompetent patient is invalid; a physician could be accused of treating the patient without informed consent if he did not obtain a substitute decision-maker.[37] An appropriate balance between respecting one's autonomy and protection from the consequences of a bad decision is what must be kept in mind. Performing capacity assessment is the only means to offer protection of the patient and physician. Therefore only patients with significant impairment should be considered incapacitated. The preciseness of the test varies with the seriousness of the consequences of the patient's decision-making.[38] Decision-making capacity should be a "sliding scale" approach rather than an either/or argument.[39]

Assessing decision-making capacity falls into four categories: the ability to articulate a choice, the ability to understand information, the ability to appreciate consequences, and the ability to manage information.[40] More formal bedside tests to determine the patient's cognitive function are available. The Mini-Mental Status Examination, even though not developed for decision-making capacity assessment, has performed reasonably well. The Mini-Mental Status Examination does not address areas such as understanding or choices.[41] The MacArthur Competence Assessment Tools for

Treatment is considered the "gold standard" for capacity assessment tools. This test does require training to administer and interpret. Additional tests available are the Capacity to Consent to Treatment Instrument and the Hopemont Capacity Assessment Interview.[42]

2. Decisions for Incompetent Patients.

Determining capacity and applying guidance standards can complicate decision-making for incompetent patients both of these will have light shed on them.

Determining Capacity.

For incompetent patients, two central ethical issues for decision-making exist: who should decide and what standards guide these decisions. If a durable power of attorney for health care exists, that addresses the first ethical issue thus supporting the value of self-determination or autonomy. It is in self-determination that one is able to exercise control over and responsibility for one's life. It may seem self-determination would be irrelevant to decision-making for an incompetent patient but that patient, that is now incompetent, was at some point competent to exercise self-determination by selecting and instructing a surrogate.[43]

If the now incompetent patient has appointed no surrogate decision-maker, then it is common to turn to a close family member to be the surrogate, which also respects the patient's autonomy. Family members are likely to know the patient's wishes and values and have the patient's best interest in mind, therefore family members may be the best suited to make medical decisions for the incapacitated patient. Decisions by the surrogate must be guided by the standard of substituted judgment, the decisions would be based on the now incompetent patients values and preferences and would reflect what the patient would have wanted.[44]

Guidance Standards.

Three distinct standards apply to certain decision-making: substituted judgment, substituted judgment combined with best interests, and best interests. Ideally these three standards should be applied in this order. The first standard, substituted judgment would presume, with clear proof, that the patient actually said what they would prefer under certain circumstances. The judgment of the surrogate should not substitute for the patient's wishes. The surrogate is only to decide what they know the patient would have wanted and would decide.[45] The second standard, the substituted judgment combined with best interests, would assume that there is some proof about the patient's preferences but not sufficient to base a decision. In this case, objective standards regarding the best interest of the patient would have to be taken in consideration. The third standard when there is no proof of what the incompetent patient would want is the best interests standard. Ideally, one would look to the purely subjective wishes of the patient but if this information is not available we have to turn to the objective best interests of the patient.[46] At this point in the decision-making process evaluating morally ordinary and morally extraordinary treatments have to be considered. The surrogate cannot legally or ethically prohibit a treatment that would be in the best interests of the patient. Beneficence and autonomy have to be considered with the incapacitated patient. [47]

To aid in the decision-making process for the surrogate, the treatment team should attempt to be as explicit about the patient's condition as possible. Treatment options need to be presented to the surrogate clearly with benefits, risks, and any other possible outcomes.[48] Outcome of surrogate decision-making can be influenced by personal beliefs, morals, and values of the health care providers as well as other clinicians, thus care

should be taken to minimize the opportunity for influencing the surrogates decisions and encouraging them to become appropriately educated to provide the best outcome for the patient.[49]

B. Advance Directives.

Second, these competency-determining challenges reveal the crucial need for advance directives. The advance directives are impacted in two ways: advance care planning and end-of-life care planning.

1. Advance Care Planning.

In advance care planning, the process and the required communication need to be discussed.

Process.

Advance care planning for patients becomes more critical as their ability to make appropriate decision choices as physical and cognitive abilities diminish. Most people want to be in control of decisions about their care. Advance care planning is preparation for future medical care when and if the patients are unable to make their own decisions. It should be part of the routine medical care conducted with their chosen medical decision-maker. It is best to approach the process of advance care planning in incremental steps. Advance care planning is a process in which patients explores, discusses, articulates, and then documents their preferences. In the process, patients identify and clarify their personal values and goals regarding their medical treatment. They articulate the care they would like and who they are comfortable speaking on their behalf. This planning should be done in a structured environment and woven into the regular care plan.[50] It is best to review the care plan and update it periodically. The advance care plan is designed to

insure that the desires of patients are respected in the event they are unable to make medical decisions for themselves. A sense of control and peace of mind are fostered by this exercise. The proxy decision-maker, by being involved in this process, comes to a much clearer view and appreciation for the desires of the patient.[51]

Communication.

Clinician-patient communication in advance care planning should involve family members, patient and proxy decision-maker. Advance care planning process centers on values, goals, and treatment preferences and provides a guide for future decisions. It has been found that people who have had these open and frank discussions commonly choose care that focuses on quality of life rather than life extension.[52] Studies have also shown that patients expect health care professionals to initiate these conversations and health care professionals, especially physicians, expect patients to initiate them. Three possible reasons why this may not be a comfortable area for physicians include (1) that they may lack knowledge and be reluctant to discuss end-of-life care, (2) that they may lack training to confidently speak of advance care planning, and (3) that they are not compensated for their time involved in these discussions and may feel death is not an appropriate outcome of care.[53]

Advance care planning is important for physicians. They have a legal and professional responsibility because patients have a right to participate in the planning of their own health care. This planning helps build trust and confidence with the physician to better appreciate and understand the values, goals, and preferences of patients. This process fosters open and frank conversations eliminating anxieties and fear for both participants. The advance care planning is preventive medicine.[54]

Even if advance care plans and advance directives have faithfully been executed, they are often not followed. Family input is often a complicating aspect. Physicians are often likely to follow family preferences rather than the advance directives. Sometimes physicians follow their own values and choose not to implement directives they find objectionable. Litigation fear also can play a role in not following the advance directive: "Live people sue; dead ones don't." Advance directives should be executed long before the end of life is imminent. Delaying the conversation until hospital admission is too late in the process as patients can be overwhelmed with making other decisions.[55]

The Church has been moderately active in securing and encouraging parishioners to engage their families and physicians to have frank and honest discussions regarding their end of life wishes. The Church is very explicit about looking at life as a precious gift from God and that humans are stewards of life rather than custodians. Preservation of life is a duty and all are expected to use their lives for the glory of God. Likewise, preservation of life is not absolute and may be rejected if it is deemed insufficiently beneficial or excessively burdensome. “The task of medicine is to care even when it cannot cure.”[56]

2. Care Planning at the End-of-Life.

To adequately advance care plan at end-of-life a discussion will ensue regarding choosing a surrogate and the Patient Self-Determination Act.

Choosing Surrogate.

In the realm of advance care planning, there are two kinds of advanced directives. First is the proxy or durable power of attorney for health care. The second, treatment

directives are instructions regarding the care of a person that becomes incapacitated and cannot make appropriate health care decisions.[57]

Adult individuals who are mentally competent to make health care decisions for themselves have a right to do so. If incapacity should occur, an individual needs someone to make decisions for them. Two types of surrogate decision-makers exist for health care, a court appointed surrogate, guardian, for individuals whose incapacity has been determined, and surrogate decision-makers allowing a competent person to designate someone else as their attorney-in-fact. The second differs in two significant respects. First, the individual not the court makes the decision. Secondly, the principle chooses the specific power to be delegated. Additionally, their attorney-in-fact survives incapacity.[58]

Choosing a surrogate decision-maker is an extremely important decision because one is giving them the authority to make life-and-death decisions. A surrogate will be making decisions based on substituted judgment.[59] One must make sure the person chosen is willing to perform that task. The person chosen must be willing to talk with you and know about your wishes, will understand what you want and your priorities about health care and will exercise your wishes. One must choose very carefully because you are entrusting someone with your life.[60] Choosing someone who can be a strong advocate and can handle conflicting opinions from family, friends, and medical personnel is paramount.[61]

Patient Self-Determination Act.

Since the passage of the 1990 Patient Self-Determination Act, advance care planning has been recognized as a means of improving decision-making at the end-of-life. The goal of the Patient Self-Determination Act is to ensure patient preferences guide

medical care in the event of their incapacity.[62] People may want and expect to control decisions about their medical care throughout their lives, but many factors work against realizing that goal. Many people nearing the end-of-life are not able to direct their medical care because often they do not realize that end-of-life is nearing. The advance directive was developed to aid people when they are fully competent to make the determination of their desires when they no longer can communicate their authentic wishes.[63]

Advance care planning should involve family members and clinicians and can start at any state of health and age. Life's goals, values, and treatment preferences are at the center of any discussion. The information gained in periodic revisiting will give an opportunity for matching subsequent care decisions with the wishes of the patient. Patients that have executed an advance directive are more likely to receive end-of-life care consistent with their preferences.[64]

Most physicians avoid end-of-life discussions until death is near. End-of-life discussions should take place during periods of relative medical stability and not in hospital settings. Medical deterioration is the reason the physicians will finally have the end-of-life conversation. The primary care physician rather than an institutional physician is best equipped to have conversations about patient's values and goals at end-of-life. As previously noted, most often patients expect physicians to initiate the end-of-life conversations and physicians expect the patient to initiate. The lack of knowledge and training is most often given for the reluctance of physicians to discuss end-of-life care. Other reasons for avoidance of the end-of-life conversation by physicians are that (1)

advance directives are not necessary for young and healthy patients and (2) the physician is not compensated for the time involved in these discussions.[65]

Strong views are expressed when asked about what kind of care people want when they are seriously ill and approaching death. They prefer to die at home and remain in control of decisions about their medical care but that is quite opposite of the facts: nearly 25% die in nursing homes and another 25% die in the hospital.[66] Nearly 40% of all adult patients in a hospital setting are incapable of making their own medical decisions. The reasons for these abhorrent statistics are multiple: lack of awareness on the part of the patient and families, unwillingness to adhere to patient's wishes by clinicians, lack of institutional support, including resistance within the medical community for completing and following advance directives.[67]

Less than 30% of the population has completed advance care planning while 90% believe having the conversation with the family is important. But that same report said they would sooner concentrate on staying alive than talk about death and completing directives. Most frequent conversation about advance care planning focuses on people who want to avoid intensive and non-beneficial medical intervention but it is clear that many worry about being denied care or being "given up on" too early.[68]

A living will and a durable power of attorney for health care offer a significant impact on the outcomes of decision-making. In keeping patient's wishes, advance directives are positive tools and more patients should avail themselves of them. The health care system should be allowed the time, the space, and the reimbursement to aid people in planning appropriately for the end-of-life.[69]

III. Clinical Ethics Consultation.

An inherent relationship exists between clinical and organizational ethics. Thus an ethics infrastructure is an essential component of an organization's ethics integration and strategy. The ethics infrastructure links fundamental processes in clinical practice to the mission and core values of the organization. To accomplish effective clinical ethics consultations require examining three related topics: the ethics approach, the quality and professionalism, and case analysis.

A. Ethics Approaches.

First, the focus of ethics approaches engages two foundational issues: ethics consultation system and the Veterans Health Administration.

1. Ethics Consultation Systems.

A discussion of ethical dilemma analysis and various models within the ethics consultation system will be discussed.

Ethical Dilemma Analysis.

Modern medical ethics depend on moral principles that respect autonomy, beneficence, non-malfeasance, and justice. In clinical medicine, which is intensely practical, one may find these ethical principles and the theories behind them too cumbersome to apply and utilize quickly to assist in making ethical decisions. Thus, ethical dilemmas can be analyzed by the means of the four following topics: (1) medical indications, (2) patient preferences, (3) quality-of-life, and (4) contextual features. Medical indications include the usual content of a clinical discussion: diagnosis, prognosis, and treatment of a medical situation. "Indications" refer to the diagnostic and therapeutic interventions. Patient preferences, patient's values and assessment of burdens

and benefits are all ethically important. A goal of medical intervention is to restore, maintain, or improve quality of life. Therefore, the patient's quality of life must be evaluated and considered. The contextual features are the social, economic, legal, and administrative context of the patient's case.[70]

Models.

Three distinct models exist to accomplish ethics consultations: an individual consultant, an entire ethics committee, or the consultation team. Because each model has advantages and disadvantages, health care organizations should determine which is most appropriate in specific situations. An individual consultant model is when one person, an independent consultant or member of the ethics committee, performs a specific consult alone. A second model is one in which an entire ethics committee jointly provides the ethics consultation. This committee is a stable group of people made up of usually six to twenty numbers. The final model, the consultation team, is the most adaptable to many situations. The team should be comprised of a physician and individuals from other disciplines, such as nursing, social work, etc., offering different perspectives, mutual support, reflection, adaptability, and timeliness are the key components to the effectiveness of this model.[71]

2. The Veterans Health Administration System.

The Veterans Health Administration System has two effective models for approaching ethical dilemmas: the *IntegratedEthics* model and the CASES approach. These two models will be discussed in a related manner.

***IntergratedEthics* Model.**

The *IntegratedEthics* model is a significant departure from the traditional approach of ethics in health care organizations. This model has received positive press nationally and internationally having become recognized for his innovation and comprehensive design impacting multiple areas of health care. *IntegratedEthics* methods and tools have been validated through testing and demonstration and thus been proven to be authenticated and valuable. With Veterans Health Administration System's excellent reputation for addressing ethical concerns, it developed an approach to ethics it is called *IntegratedEthics*. This methodology provides a significant paradigm shift: a unique and innovative way to address ethics in health care. *IntegratedEthics* changes the focus of ethics in health care from a reactive, case-based encounter, often fraught with a fragmented approach, to one that adopts a proactive and comprehensive method.[72]

CASES Approach.

The Veterans Health Administration System has a five-step approach to ethical consultation, known as CASES: (1) clarify, (2) assemble, (3) synthesize, (4) explain, and (5) support. This process offers an exemplary guide for other Health Care Ethics Consultants. Not every situation will lend itself to using all five steps, but it would behoove one to systematically work through these relevant steps when confronted with ethical health care decisions.

The first step is to clarify the request given to consultants. A preliminary understanding as to why the ethics consultation is needed and what should be the mode of action. In clarifying the request, it should be determined whether or not this is a request for resolution of an ethical concern. If not, then assistance needs to be given to direct the

requester to the appropriate offices or programs.[73] If the case were an active clinical one, then it would require the suggested CASES process. If this were a non-active clinical case, it would be considered a non-case consultation and may not require the full use of the CASES approach. Non-case consultations may involve answering questions about ethics, interpreting policy and reviewing documents from an ethics perspective. Other issues may consist of organizational ethics concerns or ethical analysis on a hypothetical or historical question.[74]

Case consultations lend themselves to the CASES approach most often, but consultations can also be very relevant in non-case consultations. The CASES approach should be used when deemed appropriate. Additionally, in the clarifying stage, ethics consultants should establish a clear statement of goals. The role of the consultant also should be explained. At this point in the process, an ethics question should be formulated which allows all involved to work productively toward a resolution.[75]

The second step in the CASES approach is to assemble pertinent information. At this point, the consultant needs to determine the types of information that needed, such as medical facts, patient values, and information about other parties. Visiting patients face-to-face is always desirable because certain information can be gleaned from that encounter. Even if the patient is nonresponsive or not interactive, there can be many useful pieces of information gathered. Access to the medical facts through the medical records and the patient's chart are essential in making a competent ethics consultation. Likewise, staff and family members need to be interviewed to gain insight into the patient. Verifying all the information gathered is important and carefully sorting through facts from value judgment prospective is essential.[76] In this phase, the Health Care Ethics

Consultant must help others become aware of their own moral views and must be attentive to the following factors: (1) each individual's understanding of the issues, (2) how the issues have arisen, (3) the individual's perceptions, and (4) the stakeholders understanding of decisional factors. By engaging in the discovery of the personal, religious, and emotional values of the stakeholders, the Health Care Ethics Consultant can listen attentively and begin to determine potential resolutions.[77] Consultants should always explain their role, explain the ethics question, and that the charge is to attempt to protect the rights and interests of all involved. They need to keep in mind that participation in the consultation by all parties is voluntary. Before the patient is visited, notification of the patient's attending physician is mandatory, both as a courtesy and as an obligation, to ascertain if there are any medical considerations. Finally, after all information is brought together and verified, this information should be summarized in a clear and succinct manner for everyone's benefit.[78]

Step three in the CASES approach is to synthesize the data. After gathering all relevant information, ethics consultants should help resolve any remaining uncertainty or conflict by analyzing and synthesizing information into practical terms utilizing ethics knowledge.[79] Next, consultants should determine whether the synthesis would be best accomplished by a formal meeting, a face-to-face discussion, or in less difficult situations telephone or email. If a formal meeting is utilized, it can be intimidating and fraught with challenges.[80] If a formal meeting is deemed necessary, however, consultants should communicate with each stakeholder beforehand, allowing them to clarify and express their values.[81] Furthermore, formal meetings require ground rules and the establishment of a goal for answering ethics questions. During synthesis, or the summary of the

consultation, the appropriate decision-maker needs to be guided within an ethically justifiable range.[82]

The fourth step is to explain the written synthesis. All stakeholders should have a clear understanding of the completed synthesis. This can be accomplished by direct communication to the key participants. Documentation needs to be made in both the medical record and the consultation service record. Important information is thus communicated to involved staff and serves as an educational tool when placed in the medical record. The medical record note also promotes accountability and transparency. In the consultation service record, observations of dynamics, performance improvements, or any other appropriate comments regarding the consultation should be documented.[83]

Step five, the final step, is to support the consultation process. This last step consists of a follow-up with the participants, a critical self-review, feedback from peers, and an assessment of the participants in the case. Such elements will aid significantly in the gleaning of information to help maintain an effective ethics consultation. Lastly, ethical issues needing addressing at a system-level needs to be brought to the appropriate individual or body.[84] In this follow-up phase, it can become a complicated question as to which part or parts one must follow up; it may not be a clinical activity. Overlapping between methods and practices of an ethics consult can occur. Most often, however, the follow-up has traditionally ignored quality measures and the emphasis has been focused on the collection of data.[85]

Effective ethics consultations are essential in providing quality ethics practices and patient care. By systematically working through a well-integrated process, the CASES approach offers a means to accomplish those ends. In clarifying requests,

assembling the information, synthesizing that information, explaining the synthesis, and then finally supporting the process ensures the overall effective consultation process. Serving the needs of patients and families as well as staff and the institution with an ethical forum is a tremendous vehicle to improve patient care and to support an environment of mutual respect.[86]

Of all of the steps in the CASES approach, the formulation of the ethical question is the most important aspect to guarantee a successful outcome. Visiting the patient and then listening to the family to better understand the values of the patient is often overlooked. Participation of the attending physician and appropriate consultants are necessary to accomplish goals. Families need the input of these health care providers. Feedback and self–reflection, even though mandatory, are often neglected. [87]
Briefly, presented are the goals, models, and steps to better understanding and appreciation of ethical decision-making and the Veterans Health Administration Systems methods utilized.

B. Quality and Professionalism.

Second, accomplishing quality and professionalism is a key to success of the ethics consultation. To that end, process standards along with certification and attestation are two fundamental elements in achieving quality and professionalism.

1. Process Standards.

To effectively have process standards, goals of a Health Care Ethics Committee and knowledge and evaluation areas have to be brought to light.

Goals of a Health Care Ethics Committee.

Quality in health care is an overreaching goal of a Health Care Ethics Committee. Identifying and analyzing the ethical principles in question or the substance of the conflict enhances quality improvement. All resolutions should be done in a respectful atmosphere with all stakeholders' interest taken into account. The Health Care Ethics Committee can aid in reaching the goal of promoting ethical norms by providing education about current and future ethical concerns. Clear standards have to be established to bring about quality in health care. To establish what quality in health care means, the Institute of Medicine gives a comprehensive definition: quality is defined as the proportion to which healthcare outcomes are increased while maintaining congruency with current practices.[88]

Knowledge and Evaluation Areas.

Regardless of the composition of the ethics consultation (e.g., individual, team, committee), the American Society for Bioethics and Humanities has determined six knowledge areas necessary for operating a successful Health Care Ethics Committee service.[89] The first area of competency is moral reasoning and ethical theory including consequentialist and non-consequentialist approaches, utilitarian and ontological approaches, natural law, communitarian, and rights theories. The second area deals with common bioethical issues and concepts such as patient rights, autonomy, paternalism, surrogate decision-making advance care planning. A third area is in health care systems that include managed care, organization and administration, institutional review boards, and relevant federal and state government systems. Knowledge of clinical context implies the understanding of terms and factors that influence the process of diseases, awareness

of the grieving process, familiarity with technology, and an understanding and appreciation of various services such as long-term care and hospice care. If not competent in this fourth area, the Health Care Ethics Committee would be hampered and unable to function effectively.

Additionally, a fifth area is the knowledge of the local health care institution with its mission statement, structure, decision-making processes, and its clinical context. The sixth and final area is the ability to understand the beliefs of local patient and staff populations and perspectives. The knowledge of relevant codes of ethics and professional conduct guidelines and relevant health law are essential.[90] Recognizing that different individuals bring different strengths, backgrounds, life experiences, and varying personal attributes, each individual consultant, team or committee should aspire to be proficient in these six areas.[91]

While all of the process standards and core competencies are important, reflection and transparency are the most critical. Stagnation of the process can occur. Continual growth can only be accomplished through reflection–action. Additionally, a concerted effort to make all stakeholders aware of the availability of the Health Care Ethics Committee is needed. This awareness will also instill in the culture of a health care institution the positive benefits of Health Care Ethics Committee.

It is essential that a Health Care Ethics Committee be evaluated because of the need to be accountable and to ensure common standards. This evaluation is critical to improve the performance of the organization. Simultaneously, evaluations contribute new knowledge and better ways to provide the ethics service in the future.[92] Quality of assessment is broken down and evaluated in terms of structure, process, and outcomes.[93]

The first element requiring evaluation is structure. Structural elements of a Health Care Ethics Committee service consist of personnel, resources, environment, and the mode of documentation. Typical elements include: (1) to whom the Health Care Ethics Committee reports, (2) policies and procedures, (3) the number of individuals in the Health care Ethics Committee, (4) the members' character and proficiency, (5) available time each member devotes to the service and (6) Management support.[94]

Evaluating the quality of the Health Care Ethics Committee service with regard to structure has often met with limited emphasis due to the lack of standards. Veterans Health Administration Systems *IntegratedEthics* model offers tools to evaluate service. The most often voiced concern in evaluating a service from the structural perspective is the competency of the members of an ethics committee. Tools are available to aid in this area, such as the Veterans Health Administration Systems Ethics Consultation Proficiency Assessment Tool. Self-assessment, although convenient, may not lead to competency. Third-party involvement as well as peer evaluation may be viable options.[95]

The second element requiring evaluation is process. The quality of the Health Care Ethics Committee process, or the relationship between the Health Care Ethics Committee service and the individuals served, likewise needs to be assessed. This assessment can be viewed as to the degree in which the established standards match actual practice. Standards commonly assessed include the following: (1) timeliness of response, (2) appropriateness of ethical concern, (3) notification of stakeholders, (4) interviewing and the gathering of appropriate knowledge, (5) determining the decision-maker, (6) conducting moral deliberation and making decisions, (7) documenting and following up with stakeholders, and (8) determining system concerns.[96] Using tools that

are available, collected data can help evaluate the quality of a Health Care Ethics Committee's recommendations. By utilizing the collected data, an internal review of performance standards could be achieved. Additionally, participants could be asked to rate the service provided.[97]

The third and final area needing evaluation is the Health Care Ethics Committee service outcomes, or the results of the service provided. Outcomes include benefits and burdens to both patients and staff. In need of outcome evaluation are four areas: ethicality, satisfaction, conflict resolution, and education. In the area of ethicality, it should be determined whether decisions were consistent with ethical standards. It is highly recommended by the American Society for Bioethics and Humanities that a peer review or external raters evaluate this point. With regard to the area of satisfaction, several studies reporting the results of stakeholder surveys have shown an overwhelmingly positive satisfaction rate for the Health Care Ethics Committee service. Comparably, conflict resolution has met with overwhelmingly high ratings in surveys. Although a systematic evaluation has not been conducted in the area of education, it has been shown that education has offered new knowledge, has made participants more aware of ethical considerations, and has helped to clarify values. Because of ethics education, a positive impact has occurred on staff morale and an improvement in ethical awareness within the organization.[98]

Access can be defined as the availability to the group that it aims to serve. To this end, all relevant parties must be encouraged and allowed to request Health Care Ethics Committee services. The perception of usefulness, the ability to access, convenience, and pleasantness must be paramount for Health Care Ethics Committee services to be

effective. Services cannot be perceived as punitive. Because of the perception of being punitive and the lack of awareness of the availability of Health Care Ethics Committee services, only a fraction of the cases involving ethical concerns are ever brought for ethics consultations.[99] Evaluation of the access can be accomplished by looking at the sources of the consultations and by determining whether all areas seemed to have access to patients, families and staff.

Efficiency is evaluated in terms of cost (money, time, and effort). Return on investment and cost effectiveness is increasingly a concern in health care. While the goal of ethics consultations should not be cost savings, neither should it waste resources. Given the limited resources available, standardization of the processes can lead to significant cost savings. One of the most important efficiency and cost savings of Health Care Ethics Committee services is in the area of identifying systems' issues and education of potential sentinel events, as well as preventing unnecessary costs in the future.[100] These three areas of quality, access, and efficiency are distinct ways of assessing ethics consultation services within a healthcare organization.

Often, the evaluation of Health Care Ethics Committee services is non-existent or evaluation is only performed to answer questions such as "Will we get sued?" or "Will our health care institution make the ten o'clock news if we do 'X' or 'Y'?" These two questions are all too often the driving force behind most evaluations, rather than "How might we improve the quality of our services?" Stakeholders, staff, patients, and families are rarely polled to determine satisfaction nor informally asked to provide feedback.[101]

2. Certification and Attestation.

A discussion regarding certification requirements of consultants and an evaluation process needs to be discussed in a related manner.

Certification Requirements.

Ethics consultation training and recommendations for individual certification of health care consultants is now being proposed by a number of health care professionals. First, a formal training program should consist of standards and competencies necessary for ethics consultation. Secondly, supervised apprenticeship should include case consultations in which the apprentice serves as lead on several cases. The supervisor however would have authority to determine competency of the individual to perform ethics consultations. The training called for is one that requires Health Care Ethics Committee to participate in formal verifiable training program in bioethics. The Health Care Ethics Committee must possess knowledge in clinical medicine as well as bioethics. One must have training and proficiency in interpersonal skills such as facilitation, negotiation, and communication. In a formal training program, there should be written evaluations of the potential Health Care Ethics Committee as well as the potential consultants completion of a formal apprenticeship.

Evaluation Process.

Another way of establishing professionalism within the ethics community is attestation, the analysis of one's ability to perform a Health Care Ethics Committee consultation. This review will evaluate consultants' education, skills, and experience. Quality attestation is different than privileging within a healthcare organization and also different from formal board certification. Quality attestation falls between these two.[102]

The need to establish clinical ethics consultation accountability and transparency has become a rather contentious subject. This community has been unable for decades to come to a consensus as to whether their work and the consultants themselves should be accountable.[103] The Health Care Ethics Committee has largely been operating outside of regulations and oversight despite the gravity of their work. With findings showing that the Health Care Ethics Committees can place patients at risk, a growing outcry has been heard for some kind of standards for assessing knowledge, skills, and practice of clinical consultants. In this time of evolution in the health care industry, a significant need exists to establish quality standards for consultants who have privileges and responsibilities in providing care to patients. The clinical ethics consultants are called upon to help facilitate in a contentious, stressful and often emotional time. The Health Care Ethics Committee must be thoroughly trained in many areas and especially to avoid asserting their judgment or prejudice into emotional situations. The clinical ethics consultants' authority is procured because of education and skill not by institutional appointment. [104]

The American Society put voluntary standards into place initially in 1988 for Bioethics and Humanities. These standards were knowledge and skills-based. Even though the standards may have been helpful in skill building and curriculum development for ethics committees, they have not significantly impacted the quality or consistency of ethics consultations. Thus, a task force was assembled to help determine the best way forward. The Quality Attestation Presidential Task Force has proposed a two-part model for evaluating ethics consultants against standards established by the American Society for Bioethics and Humanities. A collection of written work with an oral exam allowing the

assessment of consultants' skills, experience, and ability to express themselves before a group of examiners is the model being proposed and currently being implemented.[105]

Portfolio review is the first step in the Quality Attestation Presidential Task Force evaluation procedures. The portfolio is used to help determine competency in a variety of clinical settings and for a range of ethical issues. It allows for a wide variation in bioethics knowledge, but the end result must be within parameters of the American Society for Bioethics and Humanities core competencies. The hope is that these portfolios will accommodate those who have learned ethics by doing and individuals who have formal ethical education. Also included in this portfolio is a curriculum vitae with copies of diplomas or evidence of completion of ethics training. It is expected that candidates have at least a master's degree in a relevant discipline. In the portfolio a summary of Health Care Ethics Committee's experience as well as a statement of philosophy must be included. A sample of six consultations with which individuals were intimately involved should also be included. Finally, three letters are required from people who are responsible for oversight of candidates' working environment.[106] After portfolios are reviewed and individuals are deemed competent, candidates will become eligible for an oral examination, which will be offered annually at the American Society for Bioethics and Humanities annual meeting.[107]

The area of attestation offers significant pause. If the goal of the Quality Attestation Presidential Task Force is to establish competencies and professionalism, then future members of the health care profession may choose not to participate. From one who has dealt with certification processes and the development of competencies, great care must be taken so that people are not discriminated against because of their

geographic location, size of their institution, or frequency of their consultations. Thus, this tedious attestation process appears to be heavily weighted in favor of large academic settings.[108]

In sum, quality, and professionalism are assured with the implementation of the process standards and competencies. Additionally, setting minimum standards through certification and attestation will aid in the competencies of the ethics consultant moving forward.

C. Case Analysis.

Third, a final integral part of an ethics consultation is the creation of a patient case analysis. For clinical ethics and case analysis to be useful, one must start with as clear a perspective as possible. Integral to case analysis are constituents features and value judgments.

1. Constituent Features.

Medical indicators and patient preferences are factors that can cause significant angst for healthcare providers and patients. It is crucial that these two areas be considered to realize the overall goal of medicine: prevention, cure, and care.

Medical Indicators.

Medical indicators are facts about the patient's condition that indicate what forms of treatments are appropriate. Medical indicators are the facts that describe the day-to-day work of clinical care. Beneficence and non-malfeasance are the ethical principles that guide these activities. Beneficence is the duty to bring improvement to the health of the patient and the non-malfeasance refer to those activities that prevent injury and reduce risk. Both of these principles combine to help assess the benefit/burden ratio.[109]

The "respect for persons principle" requires the physician to comply with the wishes of the adult patient even if the consequences are unfavorable.[110] The two ethical principles of beneficence and non-malfeasance could support an opposite conclusion. Non-malfeasance requires avoidance of harm while beneficence calls for maximizing benefits and minimizing harms. Respect for persons typically requires a physician to honor the patient's preferences.[111]

In the conventional medical model,[112] five questions are asked to secure the medical indicators: (1) what is the medical problem, (2) what are the goals of treatment, (3) are there circumstances that medical treatment would not be indicated, (4) what is the likelihood of successful treatment and can harm be avoided, and (5) how will this patient be benefited.[113]

Medicine is not abstract. Medicine deals with patients that present themselves with health issues. For clinical ethics to be effective one must start with as clear a perspective as possible. Patients should be playing an ever-greater role in the evolution of the doctor-patient relationship. There is a transition from the authoritarian physician to a model based on patient's autonomy where patients are becoming customers, collecting more information, and want to be more involved in decision-making that impact them. The principle of "nothing about me without me" is becoming the more accepted practice.[114]

Thus the term "patient-centered" care has become the new norm. The Institute of Medicine has defined patient-centered care as "care that is respectful of and responsive to individual patient preferences, needs, and values."[115] The most important aspect of patient-centered care is the involvement of patients when the patient arrives at a

crossroad of medical options. The key aspects of patient-centered care are respect for patient's values, preferences, and expressed needs. In this approach clear information, education and alleviation of angst while involving family and friends are crucial components.[116]

The comparative characteristics of the conventional medical model are provider-centered, founded on the principles of beneficence and authoritarianism, and are typically disease–oriented. In this model, treatment is the main focus, while the patient's perspective is often ignored. In contrast, the patient-centered model is founded on the principle of autonomy; it is patient-oriented and is focused on the importance of the patient and their outcomes. In this model, patient inputs are part of the decision-making and delivery of care, thus the physician and the patient share decision-making.[117] Rather than the five questions asked in the conventional medical model there are four interactive components to the patient-centered clinical method: (1) exploring the entire health experience: perceptions, history, and various aspects of illness experience (2) appreciation of the whole person: proximal and distal context, (3) searching for common ground: goals of treatment and roles of the physician and patient, and (4) enriching the patient-physician relationship: healing and hope.[118]

One of the most important elements of patient-centered medicine is a full participation of patients in decision-making.[119] Shared decision-making requires a significant change in the conventional model of the doctor-patient relationship. The patient is required to provide the doctor with preferences about the disease process and a well-informed patient is critical in the decision-making based on those preferences.[120]

Patient Preferences.

The fundamental principle of all morality is respect for persons and that every person has value and dignity. The implication of this is personal autonomy, the right of people to follow their own plan of life. Parts of that plan are the patient's preferences and choices that people make when facing decisions about health and medical treatment. Reflected in these choices are the patient's personal experience, beliefs, and values.[121]

In general, autonomy refers to the concept encompassing self-governance and self-rule. Within modern health care, autonomy has arguably been used ambiguously and inconsistently. Clarity occurs when the libertarian view of autonomy is adopted; which is associated with freedom from constraints and freedom of non-interference.[122] Autonomy comprises the right of a person to choose alternatives for their own lives and to effect self-determination. Also implied is the responsibility of others to not interfere with the exercise of one's own autonomy. Health care providers should provide the support and promotion of autonomy. Patients have interconnectedness and interdependencies with families, communities, and social relationships that need to be considered in the promotion of a patient's autonomy.[123]

From a Christian and Catholic perspective, autonomy is not absolute. One is obligated to use freedom wisely. To do the right and good thing, autonomy is necessary. The right and good thing means no self-destructive behavior, neglecting one's medical care, or participating in a lifestyle that would be deleterious.[124] But if one chooses any of these behaviors, the physician cannot impose duties upon the person. In contrast, paternalistic action limits the freedom to choose, intrinsic to being human and inherently violating the humanity of a person, a gift given by God.[125]

Health care providers need to explore with their patients the values that are important to them. It would be problematic to address concerns that are not shared by the patient. In light of patient–centeredness, there must be a strong inclination for patients to be allowed health-related practices that are most important to them. Health care providers must avoid forcing patients into pre-existing institutional molds.[126]

A person is not autonomous when they are uninformed, deceived, manipulated, or coerced. Each is an obstacle to the exercise of autonomy. Because someone is not appropriately informed does not mean they do not have capacity but instead may not have appropriate knowledge and therefore unable to exercise autonomy.[127] Beneficence and non-malfeasance are challenged when there is not appropriate informed consent.[128] Informed consent is a vital part of current medical practice; it has different meanings in varying situations. Informed consent can be used for different purposes: legal, ethical, and administrative. Legally, informed consent is the primary source of the protection of patient rights and a guiding ethical practice of medical care. Establishing the patient's right to control what can be done to one's body dates back the earliest 20th-century.[129] Additional obligations for physicians to disclose details about treatment emerged in the 1950s with a reasonable "physician" standard requiring the disclosure of information customarily disclosed by physicians. In 1975, the American courts required disclosure to a patient who would want to know information in a similar situation, the reasonable "person" standard. Informed consent protects the patient against unwanted medical intervention and safeguards autonomy and self-determination.[130]

Ethically, the purpose of informed consent is to ensure the treatment is respecting patient autonomy. The key is that decision-making is shifted away from the physician-

centered model to a patient-centered approach emphasizing that informed consent is not an event but a process. Care must be taken to ensure patient comprehension, being cognizant of patient age, education, intelligence, cognitive function, and angst.[131] Administratively, the informed consent document ensures that a consent process has occurred. Stakeholders generally agree there are four basic elements for discussion regarding informed consent: the patient has capacity, the physician has disclosed enough detail for the patient to make an informed choice, the patient indicates understanding, and finally the decision-maker authorizes the procedure.[132]

Many people are concerned that too little is left in the hands of the patient regarding informed consent. Concerns about understanding, too little information, and undue pressure from physicians are all valid. Thusly, patients should be helped and supported so that they can make good and sound decisions. If needed, patients should be confronted if their decisions are distorted or if they are not in compliance with their values. Promoting their values and helping to maintain their concept of good increases the respect for their autonomy.[133]

2. Value Judgments.

Quality of life can be difficult to define. Distinctions between quality of life are brought to the forefront to help express value judgments of the patient. Various contextual features that can influence the patient and physician are discussed.

Quality of Life.

Patient satisfaction reflects the principle of beneficence and respect for autonomy. The aim of a medical intervention is to produce patient satisfaction. Quality of life is the degree of satisfaction that the patient would experience. [134] While satisfaction is a value

judgment, it is important to provide some empirical basis using such measures as mobility, daily living activities, pain, social interaction, and mental acuity. Quality of life may be defined as multi-dimensional including social roles, physical and mental health, intellectual and social functioning, and overall well being and pain.[135] The improvement of quality of life is a fundamental goal of medical care.[136] The physician responding to a patient seeking medical attention because of their distress must respond by examining, investigating, and together deciding which of the aims give the greatest improvement of the patient's quality of life. Together the patient and physician have to determine if the quality of life is desirable, attainable, and appropriate. [137] The perspectives on quality end-of-life care fall into the following five domains: adequate pain control, avoiding prolonging life, maintaining control, relieving any burden, and enhancing loved ones relationships. [138]

When an ethicist speaks of quality of life it can be a designation of one pole of an axiological line with quality of life at one end and sanctity of life at the other end. These concepts are used to determine whether human life is to be evaluated on the basis of its quality or if sanctity is irrelevant in decision-making about health care. At one end, absolute sanctity of life would require any means to save human life. A person would never be allowed to die regardless of the quality of life. A person's life must be prolonged even if they were unable engage in any social interaction.[139] A vitalist is one who holds the belief that physical life is the ultimate value.[140] Few moralists have agreed with this position. However, some in health care approach this end of the spectrum even if medical intervention seems useless. At the other end of that ethical line is the argument that human life loses value based upon the argument that the strongest and the fittest are

the only ones to merit health care. Few moralists have adopted this extreme position nor has health care. Sanctity of life and quality of life are both very important.[141]

The Roman Catholic Tradition has rejected both of these extremes. The Church has recognized the sanctity of life, at the same time the importance of certain aspects of the quality of life.[142] In the Church's view, life never loses its value but it does allow for the benefits of continued living can be outweighed by the burdens of treatment. Allowing for the time when enough is enough and patients are allowed to die comfortably, with dignity, and where they want to die.[143]

Developing the empirical basis to evaluate the value judgment of quality of life and to assess outcomes of clinical intervention has recently emerged. Evaluating quality of life is always related to providing appropriate medical care. Six questions are relevant to identifying and assessing how the quality of life can impact ethical dilemmas: (1) what are the chances of returning to normal life even if treatment succeeds, (2) what are the grounds for the judgment of quality of life for someone who cannot make such a judgment, (3) what are the biases that might influence the providers view of quality of life, (4) what are the ethical issues arising from enhancing a patient's quality of life, (5) are there any questions raised regarding changes in treatment plans about the quality of life, and (6) are there plans of forgoing life-sustaining treatments.[144]

Personal evaluation about one's quality of life is based upon the ethics of personal autonomy. Quality of life can refer to personal satisfaction or may be referred to by an observer's evaluation of someone else's quality of life. Observers often judge a life to be a poor quality while the one living the life considers it satisfactory or at least tolerable. It is then best that the patients express their own quality of life and when persons cannot

make their wishes known other should be extremely cautious in applying their own values.[145]

An observer may have some standard that they consider desirable and the sufferer's experience falls below that standard, making for a poor quality of life.

If that were the case then again the patient must make their wishes known and observers must be cognizant of that human beings are adaptive. Quality of life also can change with time therefore; neither patients nor providers should make major decisions based on temporary conditions.[146]

Finally, patients consistently rate their quality of life much higher than do the physicians who care for them. Physicians base their assessments on disease conditions while patients take into account nonmedical factors, personal relationships, finances, and social interaction.[147]

Contextual Features.

Medical decisions are not simply choices by two autonomous agents, the physician and the patient, but choices within the confines of contextual considerations. The considerations include proximal factors such as family, financial security, education, employment, leisure, and social support. The distal factors included are community, culture, economics, health care system, social historical factors, geography, media, and the ecosystem.[148]

The assessment of the importance of all these contextual features is a crucial ethical task. Certainly the principles of beneficence and autonomy intersect at this juncture but the concept of justice and fairness has to be added and considered. In the

clinical ethics environment, the most important justice related feature is fairness, the moral characteristic that guides transactions between individuals.[149]

Of the four principles (beneficence/non-malfeasance, autonomy, utility and justice), justice is the most complex because it is a virtue and a principle. As a virtue, a trait of character, that is giving what is due each person. As a principle, rendering each their do and the treating like cases alike.[150] The complexity stems from the fact that it has no mean. All people should possess fundamental dignity but being that humans are less than perfect, it is next to impossible to be "too just". Distributive, commutative, and rectificatory are the three major elements of virtue of justice.[151]

With commutative justice, individual good, the patient is deserving of respect from the physician. The physician should act on the basis of the patient's good. In the healing process attention must be given to the patient's value system. With regard to actions, the physician holds the patient's values "in trust". To keep the patients needs and goals in focus can be a significant struggle requiring intelligence to do justice.[152]

In honoring the patient's autonomy, the autonomy of the physician can be compromised as a human being with personal values and beliefs. Demands that the physicians violate standards of care or violate a physician's conscience in the name of autonomy of the patient are unfair. In certain domains, a growing attitude exists that the physician is just an instrument of the patient's will and should leave personal morality behind. In fact the physician and the patient are moral agents, each deserving respect and justice requiring that neither impose their values on the other. It would be maleficent for either to violate each other's autonomy.[153]

To ensure justice and fairness for the elderly, the following features should be kept in mind: (1) flexibility in the doctor-patient relationship would be kept intact and individual treatment plans would be allowed to continue, (2) all people with same categories of illness would have equal access to care, (3) defining the limits of care for specific conditions would require physician involvement, drawing on research and practical experience, (4) addressing increasing health care costs with some public control, (5) advance care-planning emphasis, and (6) increased emphasis on wellness and prevention rather than prolongation of life, an emphasis on quality of life.[154] Nowhere in medicine is there more a question of justice and fairness than in the area of medical technology and its use and misuse as interventions with the aging and dying patient.[155] The use of medical technology does not equate to better care. It is not the technology but the care received that determines well-being. Personal control over the dying process is being lost.[156]

Responsible use of power by the physician for the good of their patients is medical temperance. Avoiding underuse of technology and interventions with its subsequent abandonment of patients, or the overuse of technology and interventions with its prolongation of death, seeking the correct balance of interventions and outcomes would be responsible use of power. The temptation exists to use technology rather than give oneself in the healing process, a "technological fix". The "technological fix" is generally much easier to conceive and implement than the process of true human interaction.[157]

Secular justice is practical and methodical. Others are owed their due because we want our due in return. In this view, justice is an obligation of communal living. Thus by

compliance we can assure happiness for all. Conversely, in light of revelation, justice is transformed by Christian faith, having its deepest roots in love. By not doing justice we would relapse in self-interest, turning from the love of others to the love of self. In rendering Christian justice to others, their due is not only what is legalistically owed but also what is expected by love. Christian justice's first principle is charity.[158]

In the power of Christ's healing, we are called to a special kind of love and justice. The awareness God's call changes a profession into a vocation, a fidelity to justice transformed by charity. The Christian is called to a state of sanctity, to be perfect "as the father is perfect," and to cooperate with God in God's work. The Catholic Christian is called on to help the less fortunate and expected to exercise a "preferential option" for the poor, the sick, the troubled, the oppressed, and the outcast.[159]

IV. Conclusion of Chapters 2 and 3: Critique Based on the Ethical and Religious Directives.

A. The Normativity of the *Ethical and Religious Directives for Catholic Health Care Services.*

To discuss the Normativity of the *Ethical and Religious Directives for Catholic Health Care Services* requires examining two related topics: the different categories of Normative Catholic Teaching and the history of the *Ethical and Religious Directives for Catholic Health Care Services.*

1. Different Categories of Normative Catholic Teaching.

The Catholic Church, drawing on both faith and reason, strives to create an integral vision of the human vocation incorporating everything that is good in human activity. The Magisterium considers "science an invaluable service to the integral good of

the life and dignity of every human being."[160] Additionally, the Church desires to reach out to every human being that is suffering in mind, body or spirit bringing them comfort as well as light and hope.[161]

To pursue this vision, the Catholic Tradition provides "authoritative teaching" through four kinds of magisterial statements, as codified in Canon Law. The four levels of authoritative teaching establish "the order of truths to which the believer adheres."[162] They are: (1) truths taught as divinely revealed, (2) definitively proposed statements on matters closely connected with revealed truth, (3) ordinary teaching on faith and morals, and (4) ordinary prudential teaching on disciplinary matters. To aid in clarity, these four magisterial statements have been given the names: (1) definitive dogma, (2) definitive doctrine, (3) non-definitive, authoritative doctrine, and (4) prudential admonitions and provisional applications of church doctrine.[163]

In the first category, "divinely revealed" or definitive dogma deals with truths contained in the word of God and which the Magisterium affirms to be divinely revealed, requiring the faithful to give obedience of faith. Examples of this category are the articles of the Creed, the Christological dogmas, and the Marian dogmas, the sacraments, the Real Presence, the existence of Original Sin, the immortality of the human soul, the inerrancy of Holy Scripture.[164]

The definitive doctrines are not explicitly contained in the sacred deposit of Scripture and Tradition. They are rooted in the primary points of secondary truths which necessarily follow either logically or historically, and which are needed to expound them faithfully. St. John Paul II (d. 2005) explains that such truths are the result of the Church's "deeper understanding" of her dogmas on faith and morals. These truths are

connected to divine revelation, illustrating the Holy Spirit's inspiration for the Church's deeper understanding of the truth concerning faith and morals. Although scripture is indispensable for morality, it does not necessarily provide concrete answers to current issues. Scripture must be supplemented by reason, tradition, and the magisterium otherwise it becomes a form of moral fundamentalism.[165] In Catholic teaching, scripture is not read as an independent document.[166] In this regard, Church tradition helps to interpret scripture. The more classical interpretation of this tradition is that the magisterial authority safeguards the "deposit of faith." These truths are to be shown the assent of faith, but one technically distinguished as a "firm and definitive assent."[167] The third category is ordinary teaching on faith and morals that spells out Christian doctrines. All these teachings on faith and morals are presented as true, even though they have not been defined infallibly with a solemn judgment or proposed as definitive by the ordinary magisterium. This category is called the "authentic magisterium." The authority of the "authentic magisterium" is different from Papal Infallibility. Vatican I emphasized that infallibility belongs to Papal *ex-cathedra* teachings.[168] This category of Church teachings encompasses the *Ethical and Religious Directives for Catholic Health Care Services*.[169]

The fourth category for Magisterial teaching, "interventions in the prudential order," or prudential admonitions and provisional applications of church doctrine would include any of the routine publications of the Holy See and Bishops in their diocese. The key element in this category is its contingency upon circumstances of time and place. The possibility of error at this level of teaching is stronger than any previous category.[170]

Each person must form a correct conscience based on moral norms. Conscience is the individual capacity to discern what is good to ascertain morally what action should occur. In Pope Francis's exhortation, *Amoris Laetitia*, the Church has been called to help form conscience by church teaching. Conscience can recognize with "a certain moral security" what God is asking of individuals. The role of the conscience is paramount in moral decision-making reflecting the tradition that the conscience is the final arbiter.[171] The Church respects conscience as having a crucial role in moral discernment,[172] as clearly expressed in Vatican II: "deep within his conscience man discovers a law which he must obey…his dignity lies in observing this law, and by it will be judged."[173] "It is through his conscience that man sees and recognizes the demands of divine law. He is bound to follow this conscience faithfully in all its activity. Therefore, he must not be forced to act contrary to his conscience."[174] Thus, man's informed conscience is the final arbiter. Finally, the well-formed conscience will develop not only through knowledge of the moral teachings but also through the development of and the practice of the Virtue of Prudence. Prudence enables us "to discern our true good in every circumstance and to choose the right means of achieving it."[175]

In light of these categories of Church teachings, Papal Encyclicals have special significance. A Papal Encyclical is a letter written by the Pope to address moral, doctrinal, or disciplinary issues to the universal church. Encyclicals have become the standard means for popes to exercise their ordinary (not infallible) teaching authority. The Catholic faithful is morally obligated to comply unless their conscience prudentially prevents doing so. Several points can be noted regarding papal encyclicals: (1) they carry less authority than dogmatic pronouncements made infallibly (by the Pope ex-cathedra),

(2) because they do not contain infallible teaching, acceptance can theoretically be conditional (to respect prudential decisions of individual conscience), but in practice the faithful should usually comply, and (3) the theological issues examined are not considered to be closed.[176] Many Papal Encyclicals have been used in the Ethical and Religious Directives to formulate Church teaching: Donum Vitae, Pacem in Terris, Sollicitudo Rei Socialis, Gaudium et Spes, Humanae Vitae, and Veritatis Splendor.

In the preamble of the *Ethical and Religious Directives for Catholic Health Care Services*, reference is made to the emergence of moral principles expressing the Church's teaching on medical and moral matters that developed throughout the centuries. In a statement from the United States Conference of Catholic Bishops, *Health and Health Care* presented the theological principles that guide the churches vision of health care. In that statement, all Catholics are called to share in the healing mission of the church, offer encouragement, and make a full commitment to the health care ministry.[177] Further, in the General Introduction, the laity is invited to a much more intense and broader field of ministries.[178] To continue the church's ministry of healing and compassion, by their baptism, the laity is called to participate in the health care mission.[179] With new medical discoveries, coupled with technological developments and social change. Church leaders in consultation with medical professionals review and judge these developments according to the principles of right reason and revealed truth, as explained above. Hence, the Ethical and Religious Directives represent a form of normative Church Teaching, representing the ordinary magisterium of the Church, in this case, the United States Bishops insofar as their teachings are consistent with universal Church teaching in the Papal encyclicals, (as mentioned above).[180]

2. History of the *Ethical and Religious Directives for Catholic Heath Care Services.*

The *Ethical and Religious Directives for Catholic Health Care Services* have history dating back to 1921 when the first set of medical ethical norms were compiled. These first directives did not consider scriptural and theological teaching. A more inclusive uniform set of directives was published in 1948 that was approved by a majority of dioceses in the United States. With expanding medical technology and theological clarification, subsequent versions came to fruition 1956, 1971, 1994, 2001, and our current (5th edition) directives promulgated in 2009. The sixth edition, dealing with issues of forming new partnerships, will likely be promulgated in 2018.[181]

Because of collaboration among the Bishops, Catholic health care leaders, medical professionals, theologians and ethicists, and the Holy See, the Ethical and Religious Directives have been the touchstone for authoritative guidance and ethical standards in health care in the United States. These directives constitute the normative authority of the authentic and ordinary magisterium of the Church. Moreover, these directives developed by the United States Conference of Catholic Bishops have been recognized internationally as constituting ethical standards of behavior in health care and as providing guidance on moral issues that face Catholic health care.[182]

Two issues related to potential bias can arise regarding the normativity of the Ethical and Religious Directives. First, because they are designed for Catholic health care in the United States, they necessarily reflect that perspective. In contrast, different approaches to health care elsewhere in the world may have different priorities and perspectives. Hence, the normative teachings therein may not be relevant elsewhere in

other national jurisdictions; that is for other national Conferences of Bishops to determine. In fact however, the United States *Ethical and Religious Directives for Catholic Health Care Services* have had a significant influence on the development of other forms of health care ethical directives by different Conferences of Bishops. Second, the United States *Ethical and Religious Directives for Catholic Health Care Services* bear the normative authority of the authentic Magisterium of United States Bishops. There is a form of bias here insofar as the Ethical and Religious Directives intentionally do not adopt the entire theological discussion by Catholic moralists around the topics discussed. Those debates will continue and over time impact the continuing development of future versions of the Ethical and Religious Directives. This point is explored further in the next section where the normative foundation of Natural Law is discussed. The moral stances in the Ethical and Religious Directives revolve around different interpretations of the Natural Law. On the one hand, the conservative stance of the United States Bishops and some Catholic ethicists typically reflects an approach that emphasizes the role of nature, adopting a universal perspective. On the other hand, the more progressive stance of many Catholic ethicists typically reflects a different but not contradictory approach that emphasizes the role of persons, adopting a more historical perspective. The next section explores these different yet compatible approaches to Natural Law in Catholic Teaching.

B. The Natural Law Approach.

Natural Law has two general approaches, the focus on Nature as Universal as articulated by the traditional approach of the Church's Magisterium and the second approach, the focus on Person as Historical as argued by the progressive approach in Catholic moral theology. These two approaches are not necessarily contradictory. In the

analysis that follows an explanation of the traditional approach to Natural Law is presented in a manner that can be aligned with the progressive interpretation of Natural Law. This alignment of both interpretations of Natural Law can be especially helpful for resolving ethical dilemmas in health care as discussed in the Ethical and Religious Directives.

One approach is referred to as "Natural Law according to nature" and the other approach is described as "Natural Law according to reason." The former approach focuses upon human nature as a physical reality, presenting a static and universal view of the human condition based on biology. This static approach has been referred to as physicalism. Physicalism considers "man regarding distinct faculties, each created by God with a particular goal or purpose, defined regarding the physical stature of the faculty."[183] This approach emphasizes the physical properties of actions. The physical act of the structure is what determines whether a behavior is correct or not, with intentionality secondary.[184]

The latter approach focuses on the human person, presenting a dynamic and historical view of the human condition as contributors to God's creation.[185]
At times the discussion of Natural Law can place these two approaches in opposition to each other, opting for one or the other. In this scenario, the person- oriented or historical approach to Natural Law can be construed as being in opposition to Church teaching that adopts the nature-oriented or universal stance. Such a direct opposition to Church teaching is not pursued in this dissertation insofar as Catholic health care accepts Church teaching and seeks to apply it with flexibility. By doing so, Catholic health care tries to combine the nature-oriented and person-oriented approaches to Natural Law. This is done

by discussing how traditional teaching can be extended in new ways to emerging technologies, looking at ways in which doctrine may be developed in a legitimate manner. This approach is adopted in this analysis and explained in the applied chapters of the dissertation.

However, it can be helpful to understand what the discussion of Natural Law from the traditional perspective of Catholic teaching means. At the heart of the traditional view, Natural Law is the "formal principle" that one should pursue what is good and avoid what is bad. This is a principle of practical rationality, indicating it is rational to pursue something as good and to avoid something that is bad. Nonetheless, this formal principle does not provide practical criteria to ascertain what is good.[186] In this stance that is, there is no single criterion for goodness.[187]

This focus upon human goods is at the heart of traditional approach to Natural Law. This stance indicates there are basic goods that are intrinsic aspects of human well-being. This interpretation provides a theoretical foundation for Church teaching.[188] This theory is based on the proposition that man sets out to secure things that he perceives to be good for him.[189] In this context moral norms and principles are practical and rational distinct from desires and feelings.[190] While human acts are influenced by feelings, emotions, and imagination, the basis upon which people act is the rationally perceived benefits of their actions.[191] According to this theory, moral reason seeks something that will provide a benefit regarding human well-being and fulfillment.[192] At the core of this theory is the need to respect 'basic human goods' as the basis for moral action.[193] These basic goods can be categorized in a manageable way.[194] For example, John Finnis in his book *Natural Law and Natural Rights* classifies them as life (and health), knowledge,

play, aesthetic experience, sociability (friendship), practical reasonableness, and religion.[195]

One of these basic goods that are crucial for morality is practical reasonableness that generates moral principles to guide moral judgment and action. The requirements for practical reasonableness help us to establish criteria and standards for moral judgment.[196] The requirements of practical reasonableness include the following. The first is a "rational plan of life."[197] One must have a structured set of purposes to which one should commit and which guides him through life, one must look at life as a whole and make discernments accordingly.[198] Secondly, no basic human value can be left out, discounted, or exaggerated. A reasoned plan of life should neither devalue nor overvalue any aspect of the basic forms of human excellence.[199] Thirdly, any human being can participate in the basic human good. Just as there is a reasonable capacity for self-preference, so also one has no reasonable cause to deny continuity, longevity, awareness, prosperity, or creativity to anyone.[200] The famed Golden Rule propagated in Jewish and Christian moral tradition, accompanied by the moral appeal of sacred history, should be the standard to which we show proper respect to others.[201] The fourth is detachment. Changing circumstances, relations, and opportunities impact our lives not allowing us to complete projects, sustain relationships, or fully recognize our opportunities. Therefore, an appropriate detachment is required to maintain a healthy balance.[202] The fifth requirement is commitment, which strikes an important balance between fanaticism and abdication.[203] The sixth requirement is "relevance of consequence: efficiency, within reason."[204] This requirement demands that good must be sought by not wasting opportunities. However, making this requirement exclusive is irrational and thus immoral.[205] The seventh

requirement of practical reasonableness is "respect for every basic value in every act."[206] This suggests that one should never do anything that of it causes damage to or impedes other forms of human good.[207] The eighth requirement is "the requirement of the common good."[208] This requirement holds that all basic goods are an aspect of the common good. The common good is "a set of conditions which enables the members of a community to attain for themselves objectives, or to realize reasonably for themselves the values for the sake of which they have reason to collaborate with each other (positively and negatively) in a community."[209] Following one's conscience is the ninth requirement. This requirement is quite distinctive in that one should not do what one assesses should not be done. In sum, practical reasonableness is not merely an apparatus to make morally correct judgments, but also a way of personal well-being.[210]

Coalescing these requirements of practical reasonableness fosters morality whereby basic human good flourishes.[211] The theory of Natural Law theory is philosophically grounded in reason, rather than theology. Nonetheless, the theory presents a cogent foundation for Church teaching that relies on Natural Law, including Church teaching on health care ethics.[212] Natural Law theory has remained the philosophical tradition of the Catholic Church.[213] The most challenging contemporary health care problems are addressed in Church teaching by Natural Law to urge respect for the basic rights and the equality-in-dignity of each patient, even the most vulnerable.[214]

It was indicated earlier the traditional approach to Natural Law, as explained above based on the requirements of practical reasonableness, is the basis for the focus on nature that undergirds the teaching of the Catholic Church on morality. Now it is worth

noting that the historical approach to Natural Law that focuses on the person need not be in opposition to the traditional stance.

Advocates of the personal approach acknowledge the physical and biological aspects of being human, but they assign significant weight to the personal, spiritual, and social concerns as being crucial for a sound understanding of the common good.[215] This integral approach recognizes the historic character of morality.[216] For example, Louis Janssens argues, "Ethics is fundamentally a way of living and in its growth must keep step with human life itself as it unfolds through history. That is precisely what we mean when we say that it must be dynamic, like human life itself which it directs and leads."[217] In the *Ethical and Religious Directives for Catholic Health Care Services* where Catholic moral theology is applied to dilemmas in health care, there appears to be alignment of these two approaches to Natural Law. This combination of the nature-oriented and the person-centered approaches to Natural Law is effectively expressed in the classical principle of double effect.[218] This principle seeks to avoid intending actions that are deemed to be intrinsically disordered (reflecting the focus on nature) while permitting these actions to occur as side effects of another permitted action (reflecting the personal or historical approach that deals with practical circumstances). Here, a justified moral act should never be separated from intention: provided there is no intention to perpetrate intrinsically disordered action (that may occur as an unavoidable side-effect), those actions can be permitted based on the good action that is intended.[219] The classical illustration is the cancerous pregnant womb: causing the death of a fetus is an intrinsically disordered and morally forbidden action if intended; yet it is permissible as a

side-effect (via hysterectomy) that is unavoidable and unintended to save the life of the mother.[220]

This flexible approach to Natural Law that combines the nature-oriented and the person-oriented perspective is part of a broad view of morality in Catholic teaching. The Catholic stance combines scripture, tradition, reason, and experience, as well as the magisterial teaching authority, as sources of moral knowledge to help answer the question: "How ought we, who have been gifted by God, to live."[221]

C. Critical Framework of the *Ethical and Religious Directives for Catholic Health Care Services* to be Used in the Applied Chapters.

In the subsequent analysis, the normative teaching of the *Ethical and Religious Directives for Catholic Health Care Service*s is applied to the practical chapters, especially by considering the principle of double effect as combining the nature-oriented and personal-oriented approaches to Natural Law. Additionally, each main section will be evaluated as to which category it applies: A. Settled Issues in Church Teaching, B. Controversial Issues Eligible for Using the Principle of Double Effect, or C. Issues Requiring Doctrinal Development.

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Chapter 4. Reproductive Technology.

Reproductive technology raises fundamental questions about the normative framework of propagation. To adequately discuss reproductive technology requires examining four related topics: embryo and personhood, stem cell technologies, prenatal testing, and newborn screening.

I. Embryo and Personhood.

The relation between embryo and personhood integrates prenatal status and personhood with an accompanying ethical framework.

A. Embryo: Prenatal Status.

First, a consideration of the prenatal status of the embryo engages two foundational issues: the meaning of essence and the problem of dualism.

1. Essence.

The embryo's essence will be viewed from the perspective of essentialism with a biological viewpoint. When considering the personhood perspective of the embryo's essence, a sentience view will be applied.

Essentialism and Biological View.

Essentialism maintains that humans are essentially persons and could not exist without being a person at any given time.[1] A person is a being with the capacity of consciousness that is manifested in complex forms such as reasoning, self-awareness, and intentional actions.[2] One would not survive if that person were in an irreversible coma; the organism that continues breathing is not you.[3] There is implication within essentialism that one was never a newborn.[4] Another aspect of this essentialism is mind essentialism, claiming that humans are essentially minds.[5] Possessing mental life is

necessary for identity.[6] When a human being has the capacity for conscious awareness is when they begin to exist in all ways that matter. This usually occurs mid-gestation,[7] implying that we were never pre-sentient fetuses.[8] In the biological view, we are either human or animal organisms and come into being whenever the organism does. The organism persists as long as there is biological life.[9] It is easy to assume that the person originates at conception. Because of the ability for the embryo to divide into two, forming twins up to two weeks after conception, creates the possibility that human beings originate at different stages.[10] Cell differentiation begins at the 16-cell stage. Up to that point there is no specialization of cells performing distinct tasks.[11] They do not function as a single, integrated organism. This view maintains that life begins between the 16-cell stage and the two-week twinning potential time.[12]

Personhood and Sentience View.

The blastocyst (mammalian embryo) has personhood because of its qualities that give rise to moral worth. The blastocysts have the potential to become a person and therefore have the same moral value as a person.[13] The first argument for moral equivalency is because of the core biological similarity; each has a human genome.[14] Even though the blastocysts are not conscious, does not have the ability to experience its surroundings, it does not feel pain but it does have human DNA. Human developmental stages are irrelevant to their moral worth.[15] All living things have interests grounded in biological needs. If they are damaged or killed, that would be deleterious.[16]

In the sentience view, all sentient beings are capable of having feelings and that can be aided or harmed, are of direct moral concern.[17] Not only humans have moral status but also some living things have it.[18] Some nonpersons have moral status because of the

actions of moral agents affecting their quality of life thus they can be benefited or harmed. Not all living things have moral status, they have no subjective experience and no quality of life.[19] The sentience view has some advantages. One can explain why not only human persons but also sentient non-persons have moral status and should not be exploited or harmed.[20] It is very easy to reconcile with our intuitions about moral harms and benefits, partly accommodating the personhood view. Holding that all beings have moral status and that human beings have special moral status.[21] The sentient view connects well with consequentialism and with rights theories as well.[22]

2. Dualism.

In this section, types of dualism will be discussed as well as discussing animalism and how animalism can give us a true account of our nature.

Types of Dualism.

Dualism has a variety of forms: they are either ontological or metaphysical. Both of these are concerned with what really exists, while morality is concerned with how we should act.[23] All forms of metaphysical dualism commonly hold a classification of which we are identical.[24] In soul-body dualism advocated by Plato, the soul preexisted and did not entirely become corrupted by the body and would continue to live immortally. Our soul was our true nature and was opposed to the needs and desires of the body.[25] Descartes advocated for the mind-body dualism arguing there are two substances: the body or the mind. He concluded the true person is thinking and the body is closely aligned. The mind and body are of different nature.[26] In Lockean dualism, a person is a thinking, intelligent being. Persons exist as separate entities from their bodies and only come to exist when capable of reason and reflection.[27] In constitutionalism, persons are

distinct and different from their bodies. In its early stages the body is not a person. A person is distinct from its constituting animal. Humans differ from non-human animals. Only humans are moral agents. If a human were identical to an animal, then the manifest discontinuity between humans and nonhuman animals would be within biology.[28] In moral dualism, personhood is a stage from which humans can come and go. Personhood can be socially bestowed or comes at a certain time with cognitive awareness. In this view, the human comes into being at the embryonic stage but is not worthy of moral respect.[29] All these views of dualism can be shown to be untenable.[30]

Animalism.

Animalism justifies that the vast majority of us (exception of twinning) began to exist at conception.[31] The human embryo is from the start distinct from its origins, mother or father. Its growth is not directed by external forces but internally to survive and mature.[32] The embryo has genetic makeup that is characteristically human. Though immature, it is a complete whole organism.[33] At the point of conception a new and distinct individual came into being as a complete living organism.[34] Animalism is how we experience ourselves and interact with other people and the world. We experience ourselves as bodily beings. Animalism gives us a true account of our nature.[35] By virtue of the human entity, developing in stages at which capacities will be exercisable, human beings develop in due course and eventually mature to be full members of their species.[36] Persons are entitled to moral respect from the beginning of their existence and should not be killed in the zygotic, embryonic, or fetal stage and should not be reduced to disposable research material due to their moral status.[37]

B. Personhood.

Second, the debate on personhood revolves around two opposing views: the secular and religious.

1. Secular View.

In the secular view, the embryos personhood will be evaluated from the time of fertilization with a fourteen-day viewpoint. When considering potentiality of embryos, discussion will view the embryos as a group of human cells.

Fertilization.

At the time of fertilization, a unique genotype is established which determines its organization and its direction. The fertilized egg, which has genetic code, will determine all subsequent cell division.[38] That genetic code is set when the zygote is formed constituting the unique individual human.[39] An individual entity is formed at the time of fertilization with the newly constituted genome that directs multiplication of cells, development, and differentiation.[40] The same living being organizes itself into the different stages of development: embryo, fetus, infant, child, and adult.[41] The President's Council on Bioethics has stated several arguments that pre-embryos are persons.[42] The first argument maintains there is identity between a pre-embryo and the adult from that particular pre-embryo. This is based on the continuity of development process. The conclusion from the argument is personhood begins with fertilization because there is no point during development that the organism changes from non-person to person.[43] An additional argument is from substantial identity. The argument holds that at all stages of development the organism possesses human being characteristics and that all human

beings deserve full respect. The pre-embryo is a human being, thus it deserves full moral dignity.[44]

In the fourteen-day view, not all fertilized eggs become individual human beings. Zygotes develop because of their interaction with other cells and environmental cues not just the genotype. The genetic makeup of the zygote does not establish the human individual because of potential for twinning or multiples.[45] A blastocyst, being one individual containing two sets of genes, suggests the genes alone do not determine individual identity. More than one sperm can penetrate the egg fertilizing it but never developing, therefore that cannot be an individual human being. Zygotes can be absorbed or stop developing suggesting they cannot be human beings. There is evidence that 75% to 80% of the early embryos die.[46] With this rate of mortality, the acceptance that these are all human beings becomes very problematic.[47] Proponents of the fourteen-day view hold that the zygote becomes biologically stable at about fourteen days. The cells begin to function and twinning can no longer occur. There is the appearance of the primitive streak, the development of specialized tissues and systems become distinct at this stage of development as well.[48] Thus this group maintains that embryonic stem cells can be removed prior to the fourteenth day because they are not individual human beings constituting personhood.[49] Many of this group argues that certain moral consideration and respect are due the early human embryo before day fourteen.[50] The emergence of the primitive streak represents a milestone in development. As a developing form of life, the pre-implantation embryo deserves serious moral consideration.[51]

Potentiality.

In the potentiality view, it is argued that the zygote is not an individual human being, but a potential human being. The potentiality argument contends that even though embryos do not possess properties now, they will potentially develop.[52] If the embryo has potential to be a person with the right to life then that right of life should be extended to any stage that the embryo will go through.[53] The argument is that one type of creature will change and has moral properties. Those moral properties pass from the first form as it progresses to another form. Potential is not an inherent property, but a projection on the future state of a current entity that may or may not come to fruition.[54] Proponents of this view argue that the zygote (embryo) and the fetus deserve protection from destruction.[55] The zygote, by virtue of its biological constitution, has the potential to develop into an individual human. It maintains this potential even if the supportive environment that surrounds it is not sufficient to maintain life.[56] Moral significance is granted to the zygote because it has the power to become an individual human being.[57] To use it in research would be wrong because that would be preventing it from realizing its potential.[58] In the group of human cells view, the early embryo is a group of cells clustered together with no differentiated cells or tissues. There is no complexity or integrated functioning of the cells. The inner cell mass is just a group of cells clustered together.[59] Developmental potential is assigned only to entire cells and depend on the interaction of the nucleus and cytoplasm. Some argue totipotency is of relevance only if it is a property of a single cell in deference to a group of cells.[60] The early embryo has not developed the primitive streak and thus is not a unique integrated individual. Maintaining that just because the early embryo has potential to become something is significantly different than being

something.[61] Using embryos for stem cell research is no different than using any other sort of biological material for research. The early embryo does not warrant any more respect and rights because it has no capacity for suffering or consciousness is the consensus have most attributed to this view.[62]

2. Religious View.

Catholic historical tradition and current views of religious traditions will be engaged to shed light on the controversy of personhood of early embryos.

Catholic Tradition.

Exodus 21:22–25 are a starting point for the view of moral significance of the early embryo in the Catholic historical tradition:

> When men have a fight and hurt a pregnant woman, so that she suffers a miscarriage, but no further injury, the guilty one shall be fined as much as the woman's husband demands of him, and he shall pay in the presence of the judges. But if injury ensues, you shall give life for life, eye for eye, tooth for tooth, and hand for hand, foot for foot, burn for burn, wound for wound, stripe for stripe (Exodus 21:22-25, NAS). [63]

This passage supports the protection of the embryo and fetus.[64] Aristotle, the first to study the development of the anatomy, believed that a man's sperm reacted with a woman's blood in her womb causing it to develop into a living being. He maintained that the early embryo was unformed until the soul enters and shapes that matter.[65] Many key theologians in early Catholic moral tradition viewed the embryo as not formed and not human until it reached gender-related points. Therefore, the unformed embryo's

destruction did not involve killing a human being.[66] Augustine followed Aristotle in thinking that the progression of life in the womb started as a vegetative existence with an animal soul and finally the human soul with complete moral value. He did struggle with delayed ensoulment but chose not to delve too deeply into when this occurred[67]. Augustine thought it wrong to destroy the unformed embryo because it avoided procreation. In Augustine's thought, it was sinful to destroy the unformed embryo but it was even a more grave sin to destroy the later formed embryo, which amounted to killing a human being.[68] St. Thomas Aquinas did not view the destruction of the early embryo equivalent to homicide but that ensoulment occurred at the time the embryo resembled human form. Destruction of the embryo after the point of ensoulment was considered homicide.[69] After the Protestant Reformation, Luther did consider it reprehensible to destroy the fetus. Calvin took more direct approach maintaining ensoulment occurred at conception therefore life began at that point. After the scientific revolution, ensoulment at conception was given greater credence supported by the Catholic Churches affirmation of the dogma of the Immaculate Conception. If Mary was without sin from her conception then ensoulment occurred at the time of conception.[70]

Current Views of Religious Traditions.

The current views of religious traditions will now be articulated to get a clear picture of the view of the personhood status of the early embryo. The Roman Catholic Tradition remains faithful to the theological and ethical conviction that the early human embryo is a human being.[71] In the Eastern Orthodox tradition, whether *in situ* or *in vitro* zygote, affirms the sanctity of life at all stages of development.[72] Protestant traditions have varying views of the moral significance the early embryos, with the Southern

Baptist Convention agreeing with the Roman Catholic Tradition. While others have taken a more liberal view in adopting the fourteen-day view and are amenable to stem cell research.[73] The Talmud, the Koran, and other sacred scriptures offer little insight into the question of personhood.[74] Scholars of other traditions take opposing views with regard to the viability and ensoulment of early embryos.[75]

C. Ethical Framework.

Third, an ethical framework has developed around the above discussions on the prenatal status and human personhood. This framework revolves around theological-based frameworks and discussion on spirituality and humanity.

1. Theologically-based Framework.

Three competing ethical frameworks regarding stem cells will need to be discussed in a related manner: the embryo protection and human protection along with the future wholeness framework.

Embryo Protection and Human Protection Framework.

The bioethical principle utilized in the embryo protection ethical framework is non-malfeasance. Ethically framing the stem cell debate as a matter of avoiding doing harm.[76] The first assumption against stem cell research from the embryo protection framework is that the embryo, from the moment of conception, has moral status. This applies to zygotes both *in vivo* and *ex vivo.*[77] At conception our origin determines our individuality, our dignity, and moral protectability. At the moment of conception three things meet: the mothers egg, the father sperm, and a newly created soul.[78] Ensoulment is not physical but metaphysical. When a unique genome and a unique embryonic individual are established then the embryo is ready for ensoulment and deserving of

dignity.[79] Secondly, to harvest the stem cell requires the destruction of an embryo thus implying the destruction of the human person.[80] The third assumption is moral status in the laboratory. The embryo, *ex vivo* or *in vivo,* has equal moral status to any human thus forbidding destruction.[81] Human protection framework's essence is to protect humanity against the forces of technology. The opponents of stem cell research utilizing this framework assume an elevated place for nature. They want nature accepted as it is with all its vulnerabilities.[82] Three pillars are utilized to uphold the human protection position: "anti-playing God," "wisdom of repugnance," and "neonaturalism." Unbridled technological advance and "playing God" are contrary to nature.[83] Genetic techno-science alienates us from belonging to nature and dehumanizes thus sounding a moral alarm to the potential harms of unnatural intervention. The fundamental concern of the pillar of "wisdom of repugnance" position is the potential harm. With neonaturalism, technology threatens to denaturalize humanity. In both religious and secular there is a threat to our humanity because of biotechnology.[84]

Future Wholeness Framework.

Medical benefits and the vision of what humanity can and should be is the driving force for the future wholeness framework. What is envisioned is not only physical healing but also abundant life, a transformed future.[85] In this framework not pursuing stem cell research, with its potential for relieving suffering and enhancement of humanity, would be immoral.[86] With the justice issue, supporters within this group agree that universal access is a moral imperative. A central ethical issue of distributive justice is the inability of most to access new research and therapies.[87] Not only does this group utilize the ethical principle of beneficence but also from the religious perspective of a

response to God's call. God's will is affirmed by the drive for stem cell research. Supporting science is an act of stewardship. Humans are called to be co-creators. We have been called to be creative transformers and good stewards of the God-given talents bestowed on us.[88]

2. Spirituality and Humanity.

The Spiritual Soul and Human Dignity will be discussed to further illuminate what is at stake in stem cell research.

Spiritual Soul

The Spiritual Soul refers to the inner most essence of an individual. The soul connotes who each of us is, a centered self. Our soul becomes immortal because of our relationship to God. Our soul is *forma substantials,* a spiritual and an immaterial thing.[89] The soul resides within the body but the soul itself is not a body. The soul is where our identity resides. The soul does not come from eternity; the soul begins when the body begins. A brand-new soul is created for each individual human. The soul lasts forever but it has a beginning.[90] The soul involves concepts of great complexity going beyond anything that we are able to treat with adequacy or precision. The soul has a dynamic and developing character. As one gains new insights and memories the "real person" grows and develops; there is an unchanging component of the soul, the personal signature that guarantees identity. A portion of unchanging dimension of the soul is the individual genome.[91] The spirit is our ability to relate with God and our fellow man. It is the dimension that unites us with others. The spirit reminds us that we are in relationship with others as well as being connected to something bigger than ourselves.[92] Moral personhood is necessary and sufficient only after ensoulment. Ensoulment picks out the

moment in which the soul is first united to the body. The fetus becomes a person at the moment when it becomes a composite of body and soul. The soul is the seat of both self and agency.[93] The question of ethics, intersecting with theology regarding stem cell research, is determined when is the moment of metaphysical ensoulment, when the Spiritual Soul is implanted.[94]

Human Dignity.

Some would argue that Human Dignity requires possession of a group of capacities. Humans do not require a fixed number of capacities to be given dignity. They do need some of these capacities but not all. Even those that might be disabled or with limited capacities and might develop these in the future deserve protection and treated with dignity.[95] To further exacerbate the concern of human dignity is in the mingling of bodily materials from differing living beings. The question is the transferring of certain human stem cell materials to nonhuman hosts. The concern becomes the ethical issue of stem cell studies that would create human-nonhuman chimeras that would question the necessity of deserving Human Dignity.[96]

Dignity plays the role of protector. Dignity refers to our inherent value and cannot be reduced to ones instrumental worth. Thus we are always worth more than our possessions or functions. The person is never just a means; they are always an end. As Kant would argue from his formula of humanity, treating people as a means to an end rather than as an end in themselves is not acceptable. He argues that all humans must be treated as ends in themselves and conception is responsible for the beginning of a person thus deserving recognition.[97] That intrinsic value is what makes up Human Dignity. The question is whether dignity is intrinsic or conferred. It is both**.** Theologically, we believe

that God confers human dignity and because God has treated us with dignity we can confer it to others.[98]

II. Stem Cell Technologies and In Vitro Fertilization.

The previous section on the personal or "ensouled" status of the human embryo raises significant ethical issues for human embryonic stem cells and in vitro fertilization. The most intense debates engage three related topics: the relevance of personhood, the resourcing of stem cells, and in vitro fertilization used for embryo health.

A. Relevance of Personhood.

First, the relevance of personhood in the debate on stem cell technology engages two foundational issues: the secular view and the Catholic view.

1. Secular View.

Within the secular view of personhood two topics need to be discussed: the discord in definitions and the utilitarian view.

Discord in Definitions

A consensus on the definition of personhood has not been achieved. Various criteria are debated in the literature for determining personhood, from physical development to mental capacities. Some hold that human personhood is synonymous with human DNA, which means that personhood would begin at conception. In defining personhood, an "identity problem" exists. Comprising this term is a number of distinct yet interrelated issues. What is it that makes me a single person persisting through time with a single identity? Is it my body or is it my mind? At what point does one begin to be a person, and can a fetus or severely demented individual really be described as one? Adopting a biological-based approach is one way to approach the identity problem. In

this approach, it is asserted that one persists through time as a single human individual due to the singularity of one's human body. Even if an individual may be said to be a different person over time, one's biological identity is what is most important.[99]

Utilitarian View.

At the utilitarian end of the spectrum, personhood would begin only with one's ability to value one's own life. Many philosophers have ascribed to a performance theory to when personhood begins. Personhood can be described as when the fetus possesses a serious right to life only if it can possess the concept of self and the person must be able to recognize themselves as that entity over time. Some argue that an unborn child cannot have a desire for the continuation of life as a thinking being because the unborn does not know what life is therefore cannot desire life or its continuation. The unborn has no concept of past or future. There is no consensus on the definition of personhood and various criteria are utilized for determining personhood such as rationality, autonomy, and self-consciousness.[100]

2. Catholic View.

Beginning of life and the protection of life need to be discussed from the Catholic view.

Beginning of Life.

Semantic issues, biological issues, and philosophical and theological issues are taken into consideration to answer the question: When does life begin? Some argue that a human embryo may be considered a human being but yet not a human person. But in the classical meaning of person: the person is not simply a conscious being, but one with the power of abstract thought, concrete objects, and capable of feelings. The human person

has the ability to have abstract thoughts and possesses free will; these transcend the capabilities of any physical system and can only be explained by recognizing that the human mind is spiritual in nature. Thus it follows that the soul of the human person gives life, and is not merely an organizing principle. Assuming a material biological explanation of the human organism, eliminating intelligence and free moral decisions would be self-contradictory.[101] Delayed hominization theory of St. Thomas Aquinas was based on limited understanding of embryology by Aristotle. With advances in embryology, the Church is more confident that delayed hominization is scientifically obsolete.[102]

Protection of Life.

Human life from the moment of conception must be respected and protected. Every innocent being has an inviolable right to life. Because the fertilized egg (zygote) is a human person, we have a moral obligation to protect it. The Church takes a conservative stance in protecting potential human persons even though there may be uncertainty about when personhood begins. Official teaching states that every human life should be treated as having an inalienable right to life and be defended in its integrity from the moment of conception. Because the zygote is spiritual entails being created by God. From the moment of conception, life must be protected as a spiritual being.[103]

B. Resourcing Stem Cells.

Second, the debate on personhood clarifies when stem cells can be resourced. In the debate on resourcing stem cells, two primary sources should be considered: embryonic and adult stem cells.

1. Embryonic Stem Cells.

Two subjects need to be discussed: moral status and ethical dilemmas to engage embryonic stem cells.

Moral Status.

The ethical debate on the beginning of human life and moral value raises serious and basic questions concerning the moral status of embryos. The analysis considers whether embryonic stem cell research even if it involves destruction of embryos offers potential benefits of new medical treatments. The argument is that a moral middle ground is needed between opposite positions; the goal is to find technical ways to reap the benefits of embryonic stem cell research without destroying the human embryo. Moral value exists in the zygote itself. Moral obligation to alleviate suffering is brought to light arguing that embryonic stem cell research is a moral enterprise.[104] It is necessary to recognize the practical need for developing a reasonable policy that finds a morally correct and consistent position in dealing with human embryonic stem cell research therapy.[105]

Ethical Dilemmas.

The use of embryonic stem cells is an ethical dilemma facing America today. Increasing technology allows the ability to work with human gametes enabling us to experiment on developing human life from the moment of conception. The current debate is between the use of embryo stem cells to research possible treatments or cures for various diseases versus the defense of the personhood of the embryo. This debate can be defined in four ethical frameworks. The consequentialist ethical framework looks at the greatest good in a situation. Then the deontological framework looks for a guiding rule

that can be applied in all cases. The relativist recognizes that value can change depending on time and place. And finally, the virtue ethicist focuses on the personal character that is shaped by moral actions. Stem cells are obtained because of the desire to help people with no evil intent. Policies need to be refined to give guidance for future research and therapy.[106]

2. Adult Stem Cells.

Adult stem cells need to be discussed in light of telomeres and differential potential.

Telomeres.

In the 1980s small bits of DNA that serve as protective coverings at the end of our chromosomes were discovered, these are called telomeres. Our chromosomes are kept from unraveling by these caps. When these telomeres are healthy, cells remain healthy. The telomeres get shorter each time the cells divide and when they reach a critically short length these cells lose their ability to divide and eventually die. By adding telomerase, an enzyme, some cells can virtually be "immortalized." The only cells that benefit from this therapy are ones that divide but not all cells in the body divide. Embryonic stem cells are undifferentiated resulting in the ability to develop into very specialized cells often used for the control of certain diseases.[107] Efforts are now underway to reverse adult stem cells back to their original state called "induced pluripotency" which could eliminate the need for the utilization of highly contentious embryonic stem cells.[108]

Differentiation Potential.

Cells that self-renew and can give several differentiated cell types such as muscle, heart, and brain cells are defined as stem cells. Because of the increased interest in

regenerative medicine even more emphasis is being placed on the differentiation potential for a variety of tissue types, specifically tissue-specific adult stem cells. The adult stem cell resides in any given tissue that maintains and repairs the tissue by producing the cell types that make up that given tissue. Adult stem cells are found in bone marrow, skeletal and cardiac muscle, dental pulp, skin, liver, prostate, mammary glands, testicles, ovaries, and in several areas of eyes and ears. Adult stem cells have been well characterized and isolated to high purity from their tissue, and thus have demonstrated at the single cell level to be capable of giving rise to progeny of different cell types.[109]

C. In Vitro Fertilization and Embryo Health.

Third, the connection between the personhood debate and resourcing stem cells raises significant implications for the use of in vitro fertilization for embryo health. Hence, it is necessary to engage each point separately: in vitro fertilization and embryo health.

1. In Vitro Fertilization.

The history of in vitro fertilization and the Catholic view need to be engaged to help clarify differing points of view.

Historical View of In Vitro Fertilization.

Today assisted reproductive technology is available throughout most of the world. The refinements of technology and clinical practice have allowed in vitro fertilization to evolve into a medical procedure readily available. But it was not until 1978, with the birth of the first child, that was the culmination of decades of scientific research. Prior to that time, women considered infertile were without option other than adoption. In 1978, laparoscopic retrieval of a woman's single egg was achieved then fertilized in the

laboratory and transferred back into the uterus which resulted in the first live birth from in vitro fertilization. Further refinements of this pioneering effort have continued. The success of in vitro fertilization has unleashed a barrage of unprecedented social, ethical, and legal concerns. Debates regarding the donor anonymity, financial compensation for donor participation, the need for registry of births, third-party reproduction, and age limitations of recipients continue to stir controversy.[110]

Reproductive biotechnology has developed the traditional understanding of biology. In vitro fertilization has dramatically expanded the scale and scope becoming a platform for a myriad of human and animal applications. In vitro fertilization technology and the model of reproduction that relies upon it are commonsensical. In vitro fertilization has become a new norm in family life by establishing a new method of sexual reproduction and a powerful new window into the mechanisms of biological development. Because of in vitro fertilization, a new kind of biological kinship now exists with technology. In vitro fertilization is playing a leading role in the establishment of new technologies, remaking life as a normal, familiar, and even naturalized part human reproduction.[111]

Catholic View.

As part of one's baptismal and marriage vocation, we are called to cooperate with God in the creation of new humanity. Catholic teaching prohibits in vitro fertilization, stating that a child has a right to be conceived in the marital embrace of his parents. Human intercourse has two components, the unitive and procreative. In vitro fertilization separates these components making the procreative its only goal. Man on his own initiative cannot separate the two meanings of the conjugal act: the unitive meaning in the

procreative meaning. In vitro fertilization makes the child a commodity and makes the laboratory, doctors, and technicians part of the conception process. The Catholic Church views children as a gift from God not a right. Different reasons support the Church's opposition to in vitro fertilization include: the compromise that the procedure brings against the marriage act, the possibility of the exploitation of women, and the rights of the future fetus to be born from natural marital intimacy.[112]

The desire to have a child still is not sufficient to allow the use of any means. For the good of the family in the child, the child ought to be born of an action, which is itself, an expression of love between a man and a woman. The "divine design" of sexual intercourse should not be tampered with. Catholic teaching explains that procreation apart from intimate sexual lovemaking should not occur nor should we have intimate sexual lovemaking apart from a context of responsibility for procreation. The danger is that we will over technologize the procreative process. In vitro fertilization can pose the problem of positive eugenics-preferential breeding superior genotypes. Another area of concern is the loss of fertilized ova. The problem of embryo loss raises the evaluative question of how we are to assess human life at the embryo stage.[113]

2. Embryo Health.

The discussion of embryo health has two components that require discussion: regulation and again the Catholic view.

Regulation.

To help minimize errors, governments have instituted regulations of the in vitro fertilization industry and significant progress has been made in accreditation of in vitro fertilization labs as well. National and international professional societies have made

significant progress in the promotion of quality management, risk management, and safety. Quality systems implementation still has meaningful work to accomplish before industry understands and appreciates the need for standards. Many in vitro fertilization practitioners lack formal training and the clinics lack quality management. With the growth of this field, research and clinical practice, "corporatization" has transpired. In this process a loss of quality of care can occur because of the profit motive. Quality processes and systems cannot be applied in isolation; they must be integrated into the goal of "best practice." Because of the preponderance of staff coming from academia and research, the concepts of process and systems management are often unfamiliar, even alien.[114]

One of the most controversial recent developments of in vitro fertilization is using it to select certain genetic in embryos and, consequently, children. After sperm and eggs are removed from the donors, sperm is allowed to fertilize eggs; the resulting embryo can have one cell safely removed for genetic testing of their DNA. Preimplantation genetic screening allows couples to prevent implanting an embryo with any of undesirable genetic maladies. Preimplantation genetic diagnosis can also be used to select gender, hair color, and eye color, as well as complexion of an embryo. Preimplantation genetic diagnosis as also been approved to create "savior siblings". These could be children utilized to combat varying diseases in siblings or even potentially others. There is a striking lack of uniformity in laws and regulations surrounding in vitro fertilization. State laws vary and few federal laws exist. The American Society for Reproductive Medicine has created guidelines to ensure safety tests are performed on donated material but additional requirements for donors differ from state to state.[115]

Catholic View.

The Church does not condemn persons created by technical procedures. Those born following in vitro fertilization possess dignity and are made in God's image and likeness. Of the over 400,000 in vitro fertilization babies born annually, the concern is for the human beings created in the laboratory that will die before given a chance to live. It is estimated that only one in six embryos created following in vitro fertilization will make it to birth. Some estimates are as high as 30 embryos are created for every child born by in vitro fertilization. In vitro fertilization treats the new human being as little more than a cluster of cells to be graded, selected, and discarded. The loss of life is ignored and accepted by the in vitro fertilization industry. These failures and fatalities are not even recognized for what they are by most physicians who perform in vitro fertilization. Loss of life has become a normal and standardized aspect of the procedure. Additionally, there is significant concern for the thousands, possibly millions of human embryos who are frozen. What will be the outcome and disposition of these cryopreserved embryos?[116]

III. Prenatal Testing.

The above discussion on the personal status of the embryo and its relevance for stem cell technology connects with the ethical debate on prenatal testing as a crucial aspect of the ethics of reproductive technology. To discuss prenatal testing requires examining two related topics: the availability of testing and interventions and what may be in store for tomorrow's children.

A. Availability of Testing and Interventions.

First, the availability of testing and interventions raises two issues: options for prenatal testing and prenatal genetic interventions.

1. Options for Prenatal Testing.

The options for prenatal testing will be viewed from the non-invasive prenatal testing, the prenatal microarray analysis, and the expanded carrier screening as well.

Non-Invasive Prenatal Testing.

The genetics revolution has deluged parents with information to give greater insight into the potentiality of their children. Before discussing non-invasive prenatal testing, the definition of testing and screening need to be clarified. Testing is considered diagnostic while screening is either to screen pregnant women for specific disorders or to assess the likelihood that a fetus may manifest specific diagnosed conditions.[117] Because of the identifying circulating fetal DNA, a paradigm shift occurred in the practice of prenatal screening/diagnosis and the understanding of the fetomaternal relationship. Without being influenced by previous pregnancies, the circulating fetal DNA gives a genetic snapshot of the present pregnancy.[118] Non-invasive prenatal testing, commercially available in 2012, the American College of Obstetrics and Gynecology concluded that non-invasive prenatal testing should be offered to patients who may be high risk for fetal aneuploidy (abnormal number of chromosomes). The American College of Obstetrics and Gynecology stated that only after informed patient choice and not part of a routine prenatal lab assessment that non-invasive prenatal testing be performed.[119] Fear exists that non-invasive prenatal testing will move from uncommon to routine and that it is a modern-day cover-up for eugenics.[120] Being that non-invasive prenatal testing is easy and safe and can be performed early in pregnancy, there is fear that informed consent may become much more difficult.[121] Testing and selective abortion will become normalized. There is fear that there will be a trend towards accepting and

utilizing testing for minor abnormalities and nonmedical traits.[122] Additional fears are that new genomic technologies will allow for broader ranges of abnormalities thus causing the number of selective abortions to increase dramatically. By enlarging the scope of non-invasive prenatal testing, informed consent will be more difficult and challenge the notion of non-invasive prenatal testing serving reproductive autonomy.[123] Unsolicited knowledge of traits found by non-invasive prenatal testing would be considered an invasion of the autonomy of future children potentially revealing information about abnormalities including late onset diseases.[124] Non-invasive prenatal testing should only be offered with education, informed consent, and with counseling provided by a certified genetic counselor.[125] In prenatal microarray analysis, a molecular-based technique, a sample of DNA is compared to normal genome to determine abnormalities. Not only as a prenatal diagnostic test, this technology has been used for children with delayed development, autism disorders, and other anomalies.[126] Microarray analysis can detect genomic abnormalities that are 100 times smaller than those identified by karyotyping, the routine test used in the past. Microarray testing has a higher sensitivity to detect chromosome deletions, duplications, and unbalanced rearrangements. It also offers a shorter turnaround time because the DNA isolation procedures can be automated.[127] One of the disadvantages of the microarrays is its inability to detect balanced chromosome rearrangements and that design of the array is crucial.[128] In the prenatal setting, microarray analysis has been highly debated and thus primarily used in pregnancies that are of high risk.[129] Like non-invasive prenatal testing, microarray analysis raises many ethical questions. Informed consent along with a detailed discussion about the varying degrees of severity, purpose of the testing, and other conditions that

may be brought to light are essential. Pre-and post genetic counseling is highly recommended.[130]

Expanded Carrier Screening.

Expanded carrier screening has been available and utilized for the last ten years. Because of next-generation sequencing methods, the screening is shifting from ancestry based to one that screens many disorders.[131] The benefit of expanded carrier screening is in the decreasing of inherited genetic diseases. Practice guidelines for screening continues to be directed at high risk population groups such as Jewish women being screened for Tay-Sachs disease and African-American women for sickle cell disease.[132] Additional screens have been put in place for cystic fibrosis and spinal muscular atrophy that are recommended for women of non-Hispanic European American decent.[133] Concerns exist about the interpretations, lack of guidelines, and applicability.[134] It is essential that the informed consent be secured from patients considering expanded carrier screening. Multiple challenges occur in securing those consents because the screening can include multi-disease screenings thus truly informed consent can be difficult to achieve.[135] The ethical principles of prenatal testing and screening have to be considered. Questions arise to whom should these principles be directed: the pregnant patient, the fetus or the couple.[136]

2. Prenatal Genetic Interventions.

In the field of reprogenetics, we have the ability to create certain kinds of human beings. In this section, we will consider prenatal genetic diagnosis, prenatal genetic therapy, and prenatal genetic enhancement.

Prenatal Genetic Diagnosis.

The testing of fetuses, embryos before implantation, and the gametes are included in prenatal genetic diagnosis. Thus far prenatal genetic diagnosis has mostly been used for negative selection: targeting genetic diseases. Moral objections to prenatal genetic diagnosis focuses on that negative selection. The three most salient arguments against prenatal genetic diagnosis are: (1) loss of support argument, (2) expressivist objection, and (3) disabilities are just differences thesis.[137]

With the first objection, because of the widespread use of prenatal genetic diagnosis, the number of persons with disabilities will be diminished. The concern is the likely reduction of the financial, logistical, and social support to the disabled would be a consequence. Using prenatal genetic diagnosis for negative selection becomes morally troubling and possibly even morally indefensible. In the second objection, the expressivist, the messaging about the value of disabled persons and their contribution to society comes into question. In the third argument, prenatal genetic diagnosis is used to implement unjust discrimination and reinforces the prejudiced against the disabled, all morally disconcerting.[138]

Prenatal Genetic Therapy.

Prenatal genetic therapy is considered experimental and only a future prospect unlike prenatal genetic diagnosis, a clinical reality. With the completion of the Human Genome Project, accelerated advancement has occurred in all areas of reprogenetics. Three types of prenatal genetic testing exist, therapy on gametes prior to fertilization, on embryos before implantation, and the third type would be therapies on fetuses by injecting genetic material. To avoid transferring to later generations, the insertion of

genetic material will be into only differentiated somatic cells.[139] Many feel that prenatal genetic testing is identity affecting. By affecting identity, the individual is eliminated and someone else is created, potentially questioning the substantial moral status of that individual. Another ethical issue regarding prenatal genetic testing is the effect on inheritability to resultant generations.[140] Additionally, there is the freedom argument that can be understood in three different ways: (1) prenatal genetic testing prevents those altered from making free choices related to the modified trait, (2) the range of behavior and life plans can be altered, and finally (3) freedom from unrealistic parental expectations and demands.[141]

Prenatal Genetic Enhancement.

Prenatal genetic enhancement poses considerable doubt when considering the best interest of the child-to-be, attitudes of those impacted, and concerns about the effects on society.[142] Objections to biomedical enhancement, particularly for perspective children have been vehement. The ills include diminishment of authenticity, widespread social stratification and inequity, threat human nature and dignity, hubristic rejection of 'the given', and potentially undermine the autonomy of the individual.[143] It is impossible to obtain informed consent from the child-to-be; the best interest standard can be the appropriate decision-making guide. But many doubt that prenatal genetic enhancement can ever be in the best interest of the child-to-be.[144] Additionally, doubts about an open future of the child produced with enhanced traits and the safety of prenatal genetic enhancement warrant pause. There is appropriate concern that parents are imposing their will on the child by enhancing their traits thus violating the child's best interest.[145] Imprecise vectors that can deposit desired genes leaving detrimental genes in place cause

much angst as to what may happen within the patient's body.[146] The unanticipated and unintended consequences are of moral and ethical concern.[147]

B. Tomorrow's Children.

Second, the availability of prenatal testing has significant implications for tomorrow's children. Here two issues must be addressed: the selection of characteristics and savior babies.

1. Selection of Characteristics.

Selecting children with specific disabilities and selecting for a specific sex need to be discussed.

Disabilities.

Two questions are raised when discussing the correctness of selecting a child for a specific disability, the using of selective reproduction techniques for selection and under what circumstances do concerns for the welfare of the children provide reasons to practice selective reproduction.[148] There are cases of what is termed wrongful life or life not worth living. These would be situations where quality of life is so difficult that they would be better off not existing. Normally cases where life is full of pain and indignity would qualify[149]. From a bioethical position, it would be wrong to create a child with that level of quality of life. In most cases though selecting for a disability would not fall into this category because of a potential positive quality-of-life that could be achieved by that resultant child.[150]

Sex Selection.

Sex selection is a bioethical example of parental choice that is technically achievable and easily delivered. Sex selection can raise the issue of sex or gender

discrimination.[151] If sex selection would reflect a discrimination against women and systematically reinforce that bias, this could constitute a moral and legal injustice to be prevented.[152] Bioethics, public policy, and law intersect on the topic of sex selection. Opinions regarding sex selection range from one extreme, saying it is always wrong and should be banned to the opposite end of the scale to those who prefer a free market.[153] Even though a portion of sexual selection would be driven by sexist beliefs and attitudes this is not enough to justify prohibition. Reproductive liberty could be deleteriously impacted.[154]

2. Savior Babies.

Instrumentalization and commodification of savior babies need to be discussed in this section.

Instrumentalization.

Instrumentalization (treating a child as a means to an end) can manifest itself for other people's well-being or satisfaction of other's desires. A savior baby (sibling) being selected so that an existing one might live is an example, although other examples do exist such as benefiting the parent's health or parent's preferences.[155] Savior sibling is used to describe a baby that is created using in vitro fertilization that has been screened during that process to serve as a donor match for a child that already exists and is sick in some way.[156] There are three compelling arguments in the anti-savior sibling controversy. First being, savior babies would be wrongfully instrumentalized, treated as mere means. This stems from Emmanuel Kant's famous dictum "Never use people as a means but always treat them as an end."[157] Second, savior selection would have a negative effect on the moral climate and society. Claiming that society would become less fair and equal

and lead to the development of a genetic underclass. Also potentially leading to the acceptance of customized conception and designer babies.[158] Finally, concerns about the welfare of the savior sibling and the fundamental issues relating to the welfare of that child. Two harms are most concerning: the physical harm directly caused by the prenatal genetic diagnosis and the psychological harm created by being a means to an end.[159]

Commodification.

Commodification has three essential characteristics: (1) it has a price, which a seller is willing to receive, and the buyer is willing to pay, (2) they are fungible, interchangeable with other goods, and (3) their value is instrumental not intrinsic.[160] In the normative sense, commodification is a social practice which one gives rights over to the thing in question that are bought and sold. There is no moral judgment just a matter of fact that certain things are being treated as commodities.[161] Commodification has two forms: complete modification (commodification with no restrictions) and incomplete commodification (commodification with restrictions).[162] These distinctions allow us to focus on the moral basis for treating these body parts as commodities. In the libertarian political thought, bodies and body parts may be bought, sold, and rented.[163] Commodification in the moral sense is to disapprove and point out the unique kind of wrong: the wrong of commodification. Wrongful commodities are things that are treated as commodities but are really fungible or have instrumental value. When commodification is cited in nonmonetary context one is actually appealing to instrumentalization and treating things as fungible.[164]

IV. Newborn Genetic Screening.

Closely related to the ethical debate on prenatal screening is the debate on newborn screening, which requires examining two related topics: screening programs and screening consequences.

A. Screening Programs.

First, to understand screening programs it is important to engage two pivotal issues: the national research framework and the future of genetic screening.

1. National Research Framework.

The current overview of genetic screening and the challenge of research for newborn screening will be engaged.

Overview.

To begin an overview of genetic screening we start in the 1960s when a simple blood test to detect a genetic metabolic disorder, phenylketonuria, and a genetic disorder that can lead to mental retardation was developed.[165] To treat phenylketonuria, a special diet begun early in life can reduce the major symptoms.[166] States over time introduced this test and made it mandatory. Some states began to expand newborn screening to other tests for other disorders.[167] In spite of federal funding, newborn screening is primarily a state public health activity; thus states have made different decisions about the content of their screening, treatment protocol, follow-up, and the cost to newborns families.[168] The goal of screening is improve the health of the child and appropriate only for medical conditions that have effective treatments.[169] This consensus has now come under pressure with the calling for broadening the focus to diseases with no current treatment as well as to the families for screening for untreatable genetic disorders. The implication here is

identifying parental carrier status of genetic disorders that might later impact reproductive decisions.[170] A salient issue has been the fairness and the inequity of cost. While one of the most controversial issues is that compulsory screening and its practice of being performed without explicit consent. Many questions are left unanswered such as the right to refuse, the right to confidentiality and privacy, the right to information, and even methods of delivery. These and others make developing sound ethical policy a significant challenge for screening programs.[171] Finally, an issue of overarching importance in the discussion of newborn screening is that of race, ethnicity, and social economic status. Included in that discussion is the important question of targeting particular groups or the screening of all newborns.[172]

Challenges of Research.

Many barriers exist creating challenges of research**.** Especially in establishing value of prenatal genetic screening programs. One of the basic questions is whether morbidity and/or mortality are reduced as a result of screening. State health programs typically are underfunded thus evaluation of established programs become problematic. Although diseases can be detected in affected children and that interventions can be lifesaving, the benefits of population screening programs remain uncertain with regard to the long-term benefits.[173] Exacerbating the challenges of research with human bio specimens gives rise to several ethical issues such as informed consent, privacy and confidentiality, ethical reviews of research proposals, access to the results, and any other benefits gleaned from that research.[174] The obtaining of informed consent from participants in research does satisfy the ethical principle of respect and honors the individual. By obtaining informed consent there is acknowledgment that autonomous

decisions regarding one's body have been discussed and determined, reflecting transparency.[175]

2. Future of Genetic Screening.

Movements toward expanding newborn screening and the whole gene sequencing will impact that potential need to be engaged in this section.

Expanding Newborn Screening.

Newborn genetic screening was been born out of state run politics. State legislatures were lobbied when advocates felt the medical community was not moving rapidly enough in expanding newborn screening.[176] Over time advocates have remained involved bringing pressure on states to add other disorders to the screening panel conceivably to avert serious disabilities and even death.[177] In 1968, Wilson and Jungner published criteria for newborn screening: (1) the condition should be an important health problem, (2) treatment for the disease needs to exist, (3) diagnostic and treatment facilities should be available, (4) an asymptomatic stage should be recognizable, (5) suitable testing must exist, (6) the population must accept the test, (7) an understanding of the development of disease, (8) an agreeable policy on who should be treated, (9) costs should be balanced in relation to medical care expenditure, and finally (10) it should be a continuous process project.[178] Gradually the focus changed with the advent of new technology, tandem mass spectrometry.[179] Tandem mass spectrometry with its capability to measure potentially hundreds of metabolites at one time allows for early intervention in previously unknown disorders, dramatically improving health.[180] Thus there was pressure to add numerous tests to newborn screening panel. The American College of Medical Genetics recommended a core of 29 conditions for newborn screening. In

addition, 25 additional conditions "secondary targets" were recommended. Because of the inability to meet the Wilson/Jungner criteria analysis relied on expert opinion and resulted in considerable debate.[181] False-negatives, false-positives, over-diagnosis, findings of uncertain significance, and incidental findings all contribute to that debate.[182] With the history of the technological imperative, even with its unintended consequences, screening marches on.

Whole-Genome Sequencing.

Now the prospect of whole-genome sequencing offers the potential integration with newborn screening programs. Whole-genome sequencing can deliver useful information about poorly understood diseases and improve the prognosis of and treatment options for patients.[183] It will inevitably lead to all kinds of unsought information as well. Questions of responsible use of such testing, meaningful informed consent, and the value and disposition of the information obtained will entail complex consideration.[184] These population based genetic screens have both individual and collective implications, thus the balance of risk and benefits has to be considered not only from the perspective of individuals and families, but also from that of the target population and of society as a whole. As newborn screening programs enter the genomic era, they must focus on addressing issues of equality, access, and education that have plagued the new born screening programs since its inception.[185]

B. Screening Consequences.

Second, programs for newborn screening inevitably create concern about screening consequences. To discuss concerns about screening consequences, there are

two areas of consideration, an overview of the problem and a consideration of disease ontologies

1. Overview.

In this section, the origins and successes of newborn genetic screening needs to be engaged.

Origins.

The origins of newborn genetic screening are normally ascribed to the work of Robert Guthrie.[186] After the birth of his own child with mental retardation and a niece with phenylketonuria he became involved with an organization that fights discrimination against children with mental retardation.[187] Phenylketonuria is a genetic condition whereby an enzyme is deficient that is needed to break down the amino acid phenylalanine that can build up in the body and cause mental retardation. An experimental form of phenylketonuria treatment was a restrictive diet.[188] Guthrie developed a bacterial inhibition assay that could diagnose phenylketonuria using neonatal blood. This discovery could identify affected children and could be used as a screening method. It could discover affected children before the onset of irreversible symptoms. A simple method was developed taking blood collected from a heel stick of the child prior to hospital discharge, then sent to a lab to be easily analyzed. If the levels were elevated then the infant's physician was notified and the results were given to the family.[189] A pilot study was federally funded in 1962 to screen 400,000 infants in 29 states for phenylketonuria. Most states continued the screening after the completion of the study.[190] Later in the 70s, the federal government supported screening for genetic diseases and provided limited funding. Five component guidelines were identified for newborn

screening, including the screening itself, follow-up, diagnosis, therapy, and evaluation.[191] Since phenylketonuria screening began, various tests have been added and screening has remained largely a state responsibility. Because of that autonomy, each state has chosen the screening targets, payments, education, and follow-up. This variability of screening has left a patchwork of coverage in the United States.[192]

Successes.

The successes of phenylketonuria universal screening has allowed universal screening to become a cornerstone public health initiative requiring collaboration of health care professionals and an advanced infrastructure including laboratories, hospitals, clinical centers, and families.[193] Because of issues not always being addressed before implementation, critics maintain it is essential that scientific uncertainties be worked before developing the health care infrastructure and investing in newborn screening.[194] As a result, three points have been established in evaluating the historical consensus regarding population screening: (1) population screening is only permissible if it addresses an important health problem and there is an accepted treatment available, (2) mandatory genetic screening should be avoided if possible but bioethical issues such as informed consent, confidentiality, autonomy, knowledge, well-being, and equity must be addressed, and (3) technological innovation should not be the driver in the expansion of newborn screening but the focus should be on an infrastructure that provides follow-ups, treatments, and health services.[195] Phenylketonuria screening has largely been a success story that celebrates the marriage of patient advocacy with concerned health care professionals to promote screening.[196] In preventive medicine few things have been done that have been as successful as newborn screening.[197]

2. Disease Ontologies.

In this section, a case will be made showing how disease ontology can be understood through newborn screening. The understanding of medium-chain acyl-coenzyme A dehydrogenase deficiency will be discussed pre-screening and post-screening to exemplify the value of newborn screening.

Pre-Screening.

In the pre-screening stage of medium-chain acyl-coenzyme A dehydrogenase deficiency, understanding of this condition was very limited.[198] The prospect of death was generally the manifestation.[199] It was suggested that sudden infant death syndrome might be as a result of undiagnosed medium-chain acyl-coenzyme A dehydrogenase deficiency. What was known was that medium-chain acyl-coenzyme A dehydrogenase deficiency was caused by mutations in the medium-chain acyl-coenzyme A dehydrogenase deficiency gene causing an enzymatic deficiency.[200] This deficiency can impact the metabolism of certain fatty acids that accumulate in the blood manifesting themselves as lethargy, hypoglycemia, liver damage, and possible brain damage.[201] The usual manifestation of medium-chain acyl-coenzyme A dehydrogenase deficiency is when a primary metabolic crisis caused a prolonged period of fasting such as may occur during an illness. As a result of that primary crisis the secondary trigger would be required for medium-chain acyl-coenzyme A dehydrogenase deficiency to manifest itself. When this episode occurred mortality rate was about 25% while others suffered significant neurological impairments or developmental delays.[202] Most thought medium-chain acyl-coenzyme A dehydrogenase deficiency was a result of a founder effect most commonly seen in non-Hispanic white populations of northwestern European descent.

The only treatment was a low-fat diet and avoidance of fasting especially when the patient becomes ill and stopped eating. The disease would manifest itself most often before age six but could possibly remain a possibility as an adult.[203] With confirmation through biochemical testing, an abnormality was discovered that had a common genetic profile. By DNA sequencing, the case was made for large-scale newborn screening.[204]

Post-Screening.

Post-screening of newborns has shown several medium-chain acyl-coenzyme A dehydrogenase deficiency variants that were previously unknown. Additionally, medium-chain acyl-coenzyme A dehydrogenase deficiency has been broken down into carrier like, intermediate, and severe by correlating 75 genetic mutations many of which had never been documented.[205] After screening, it was determined that instead of 80% to 90% of the medium-chain acyl-coenzyme A dehydrogenase deficiency patients had a particular mutation that only 50% actually possessed it. This mutation, along with other mutations, was thought to be unique to northern Europeans. Subsequently, it has been found these mutations are twice as prevalent throughout the world.[206] The saliency of ethnicity in genetics is now becoming more apparent because of this screening.[207] As a result of screening, treatment regimens have been adjusted to allow for changes in frequency of feeding.[208] Also revealed, the severity of cases has been found to be milder then previously assumed. Geneticists have found more and different diseases. Diseases have split into variants while others have disappeared and now are being redefined as oddities with no clinical implications. Geneticists because of newborn screening have a better understanding of diseases like medium-chain acyl-coenzyme A dehydrogenase deficiency and have adjusted treatment regimens accordingly.[209] The knowledge gap has been closed

by more information sharing by discussions, assessment, diagnostic testing, and appropriate management.[210]

This chapter has considered major issues in reproductive technology that have significant applications for the Catholic ethical tradition. Catholic teaching engages each of them in the dynamic manner to develop its moral doctrine when appropriate. This is based on emerging science, but also to indicate clearly where there appears to be wrongdoing from individual and social perspectives. The next chapter continues this analysis of engaging the Catholic tradition with breakthroughs in science and medicine by examining emerging issues in regenerative technology.

V. Critique Based on the Ethical and Religious Directives.

Natural Law has two general approaches, as described in the conclusion to Chapter 3. The first approach focuses on the universal aspects of human nature. This approach is typically associated with the settled Catholic teaching on morality. The second approach focuses on the person, presenting a dynamic and historical view of the human condition as contributors to God's creation.[211] This approach is typically associated with using the Principle of Double Effect to apply traditional Church teaching in a flexible manner to changing circumstances. Arising from these two approaches to Natural Law, a third approach has emerged combining the nature-oriented and person-oriented approaches to new dilemmas regarding emerging technologies that may require doctrinal development in Catholic teaching.

In the conclusion of each applied chapter, (Chapter 4, 5, and 6), a critique based on the Ethical and Religious Directives is presented regarding the main topics in each

chapter. The critique adopts the above approaches to identify three distinct categories as follows.

Category A deals with settled issues in Church Teaching reflecting the Nature Approach to Natural Law.

Category B deals with controversial issues eligible for using the Principle of Double Effect reflecting the Personal Approach to Natural Law.

Category C deals with issues requiring doctrinal development in Catholic teaching to address new dilemmas regarding emerging technologies.

The following analysis applies this threefold critique to the topics discussed in this chapter on reproductive technology. Each main section is discussed in turn.

Section I. Embryo and Personhood.

This section discussed the status of the embryo regarding its personhood. From the perspective of the threefold critique, recognizing the status of the human embryo with personhood is settled teaching (Category A).

Authoritative guidance is offered in Part Four of the Ethical and Religious Directives, Issues in Care for the Beginning of Life. At the moment of fertilization, the respect due all persons is to be accorded the human embryo.[212] The Church's Catechism also teaches that from the first moment of its existence the embryo must be guaranteed unconditional respect.[213]

Section II. Stem Cells Technologies and In Vitro Fertilization.

This section discussed the prohibition of embryonic stem cell research that destroys embryos. This is settled Catholic teaching (Category A).

Utilization of embryonic stem cells has been hotly debated and problematic for all sides of the debate regarding sourcing and using embryonic stem cells for medical purposes. Determining when personhood and ensoulment occur has complicated the debate.[214] In harvesting these cells presently the human embryo is destroyed raising two ethical questions: one of consent and one as to ending human life by destroying the embryo.[215] As is indicated by Directive # 39 and Directive #51:

> Those techniques of assisted conception that respect the unitive and procreative meanings of sexual intercourse and do not involve the destruction of human embryos, or their deliberate generation in such numbers that it is clearly envisaged that all cannot implant and some are simply being used to maximize the chances of others implanting, may be used as therapies for infertility. (Directive #39)

> Nontherapeutic experiments on a living embryo or fetus are not permitted, even with the consent of the parents. Therapeutic experiments are permitted for a proportionate reason with the free and informed consent of the parents or, if the father cannot be contacted, at least of the mother. Medical research that will not harm the life or physical integrity of an unborn child is permitted with parental consent. (Directive #51)

With the question of ending human life, it can be appropriately argued that harvesting stem cells by means that kills the organism with rational nature are morally illicit. If pluripotent cells could be procured by altered nuclear transfer, altered nuclear

transfer oocyte assisted reprograming, or from human embryos themselves that were not harmed or destroyed, then these methods could be considered potentially licit.[216]

There is an imperative to find a better way to procure cells that can be utilized to positively impact medical science and not destroy human life. If there were a potential breakthrough in securing these beneficial cells, then that may raise the possibility of a need for a doctrinal development of the traditional Church teaching, but as of now embryonic stem cell research is prohibited as settled teaching (Category A).

The second main topic in this section dealt with in vitro fertilization - the prohibition of this technology is also settled teaching (Category A).

Human Dignity is the galvanizing force for the Church's concern for the sanctity of life and comparably for the dignity of marriage. The Church cannot endorse any medical practice that compromises this teaching.[217] The Church upholds the sanctity of life "from the moment of conception until death."[218] Included in this teaching is the prohibition of in vitro fertilization as addressed in Directive #41.

> Homologous artificial fertilization (that is, any technique used to achieve conception using the gametes of the two spouses joined in marriage) is prohibited when it separates procreation from the marital act in its unitive significance (e.g., any technique used to achieve extracorporeal conception). (Directive #41)

However considered from another perspective, in vitro fertilization could become related to Category B, permissible using the Principle of Double Effect, insofar as the original prohibition of in vitro fertilization related to the context of

marital fertility (using the nature approach to Natural Law). In a different context, that is the health of the embryo, the principle of double effect could be applied to address an embryo's health rather than marital fertility.[219]

Section III. Prenatal Testing.

In this section, pivotal ethical dilemmas aligned these technologies relate to various forms of prenatal testing and screening.

First, this section discussed prenatal genetic testing. This is permissible as settled Catholic teaching (Category A).

Prenatal diagnosis of the unborn utilizing non-invasive prenatal screening and appropriate use of expanded carrier screening can certainly be ethically problematic, but Catholics cannot assume that prenatal genetic testing is automatically immoral.[220] The Congregation for Doctrine of Faith has stated: "if prenatal diagnosis respects the life and integrity of the embryo and the human fetus and is directed toward safeguarding or healing that individual, then it is appropriate."[221]

Second, this section also discussed prenatal genetic therapy. This is controversial but may be permissible using the principle of double effect (Category B).

In *Dignatis Personae*, the Church directly addressed gene therapy:

"For a moral evaluation the following distinctions need to be kept in mind. Procedures used on somatic cells for strictly therapeutic purposes are in principle morally licit."[222]

Additionally, this is addressed in Directive #51.

> Nontherapeutic experiments on a living embryo or fetus are not permitted, even with the consent of the parents. Therapeutic experiments are permitted for a proportionate reason with the free and informed consent of

> the parents or, if the father cannot be contacted, at least of the mother. Medical research that will not harm the life or physical integrity of an unborn child is permitted with parental consent. (Directive #51)

The allowing therapeutic experimentation is an indication that the Church is keeping pace with technological breakthroughs while maintaining the dignity of the human person.

Third, this section also discussed prenatal genetic enhancement. This topic likely requires (depending on the what the enhancement involves) doctrinal development (Category C).

Genetic enhancement is quite different from gene therapy. Genetic modifications risk germ cells transmission to potential offspring. The ethical critique of this topic can be described as follows: "In the present state of research, it is not morally permissible to act in a way that may cause possible harm to the resulting progeny… The question of using genetic engineering for purposes of medical treatment also calls for consideration."[223]

Fourth, this section also discussed the impact of a variety of reproductive technologies that will shape tomorrow's children. Generally, these technologies that involve sex selection or commodification are ethically controversial and would need doctrinal development to permit them (Category C).

For example, prenatal genetic diagnosis can be used to acquire an embryo that the genetically matches a sibling who has a malady needing a transplant (the so-called savior sibling debate). In this case, prenatal genetic diagnosis is used to screen for certain

genetic traits and against genetic defects. The chosen embryos are implanted and brought to term with the express purpose of becoming a tissue donor for their older sibling, while other embryos are discarded. Here prenatal genetic diagnosis is used to create human beings in a manner of selective reproduction that is very problematic for Catholic teaching.[224]

In contrast, prenatal diagnosis of the unborn utilizing non-invasive prenatal screening and appropriate use of expanded carrier screening can be ethically problematic but not automatically immoral.[225] The Congregation for Doctrine of Faith has stated: "if prenatal diagnosis respects the life and integrity of the embryo and the human fetus and is directed toward safeguarding or healing that individual, then it is appropriate."[226]

The next and last major section addresses newborn genetic screening.

Section IV. Newborn Genetic Screening.

In this section, the pivotal ethical dilemma relates to newborn genetic screening. This is permissible when used simply for screening purposes. However, this is not permissible for illicit purposes such as screening for abortion or enhancement (Category A).

Genetic testing and newborn screening provide information. The ethical issue arises regarding what is done with the information. If the information is used to discriminate, then it is morally illicit.[227] If these are done to learn more about the fetus and help the parents and doctors prepare for any complications, then they would not be morally problematic. Using these tests to come to an acceptance of a child with a disability would be considered licit.[228]

In sum, the threefold ethical critique based on the Ethical Religious Directives has been applied to the topics discussed in the main sections of the chapter. This threefold critique is applied at the end of the next two applied chapters.

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Chapter 5. Regenerative Technology.

Regenerative technology raises fundamental questions about the normative framework of genetics. To adequately discuss regenerative technology requires examining four related topics: genetic enhancement, germline genetic modification, mitochondrial DNA, and gene editing with clustered-interspaced short palindromic repeats (CRISPR).

I. Genetic Enhancement.

To discuss the ethics of genetic enhancement, the pivotal ethical topics are organized into two categories: influences on human progress (here the ethical discussion examines human development and human nature) and influences on future generations (here the ethical discussions examines identity and perfection).

A. Human Progress.

First, a consideration of the significance of genetic enhancement for human progress engages two foundational issues: human development and human nature.

1. Human Development.

The concept of human development in this context raises two related ethical dilemmas to deal with ethical dilemma and historical enhancements.

Ethical Dilemmas.

First, discourse on well-being revolves around the meaning of good. A basic benefit perceived in any genetic alteration deals with personal goods, the advantages for the individual that arise from being genetically altered.[1] This is called a Personal Goods Assumption that focuses on the risks that could harm the individual or society.[2] Another form of this basic benefit is called the Market Goods Assumption for which genetic

alterations would be market driven.[3] In these approaches, the key focus is eliminating any social harm that could arise from the enhancements.[4] Secondly, human development focuses on enhancing personal well-being:[5] cognitive capabilities, the extension of life, decreasing morbidity and disability, and advancing the immune system all could be benefits of genetic alterations.[6]

Historical Enhancements.

There is no doubt that the well-being of society has benefitted from historical enhancements such as literacy, the agrarian revolution, computer technology, and health care.[7] However, there are significant reasons to be cautious about genetic alterations that seek to achieve these human developments.[8] This caution arises out of respect for human nature.

2. Human Nature and the Precautionary Principle.

The concept of human nature raises significant ethical problems that are discussed in terms of the metaphor of playing God and the ethical principle of precaution.

Common Characteristics.

The metaphor of playing God deals with the legitimacy of humans interfering with human nature. Human nature can be described as a set of characteristics common to human beings, delineating the core difference between humans and other creatures.[9] The metaphor of playing God highlights the consequences of germline genetic modification as a major ethical concern,[10] focusing on what are specifically human characteristics,[11] and highlighting the significance of our genetic makeup as a barometer for biological limits.[12] The metaphor suggests that with germline genetic modification humanity may be usurping God's design.[13]

Precautionary Principle.

In light of this concern of humanity over-reaching its legitimate moral authority, there is an ethical responsibility to honor what is referred to as the precautionary principle. The precautionary principle specifically focuses on risk reduction in any germline genetic modification.[14] This principle places the burden of proof on those engaging in germline genetic modification to justify change to individuals, society, or the species.[15] They should prove that the changes would not cause unacceptable harm.[16] That is, the principle encourages the use of risk reduction principles.[17] Some critics of using this principle argue that precaution can lead to paralysis,[18] focusing too much on potential calamity without sufficient consideration of benefit.[19] Moreover, critics claim that for practical reasons the principle is unworkable.[20]

B. Future Generations.

Second, the impact of germline genetic modification on human progress raises the question of influencing future generations focusing upon the significance of identity and perfection.

1. Identity.

The concept of moral identity raises two critical issues: enhancements that are supernormal and enhancements that deal with disease avoidance.[21] Enhancements would be for individuals and as well as species.[22]

Supernormal Enhancements.

In particular, risks to biological development and their psychological impact are especially important.[23] Three moral arguments against supernormal enhancement emerge: the goals of medicine and enhancement are incompatible, the Positional Goods Argument

(giving one person an advantage over another), and the argument that enhancement generates inequality,[24] especially insofar as benefits of enhancement typically will accrue to individuals.[25] The issue of authenticity is especially significant for discussions of identity,[26] not least because of the link with character.[27] In addition to the obvious concerns about accumulated long-term effects, [28] the meaning of an individual's moral status is central to the ethical debate on identity.[29]

Disease Avoidance Enhancements.

In addition to addressing enhancements that are supernormal, the debate over identity also deals with enhancements related to disease avoidance based on the resulting impact on human traits.[30] Here the ethical debate revolves around therapy (healing a pathology), functionality (improving the human functioning), and transhumanism (changing human nature).[31] While advancement in therapy would be generally welcomed,[32] transhumanism elicits much concern in part because of the ambiguous meaning of a projected superiority among some humans,[33] and in part because of the point made previously about the moral status of human individuals.[34] In this regard, one response from transhumanism advocates is ethically disconcerting: that future generations have no moral claim or rights in current considerations because they do not exist now.[35] Not surprisingly, this discourse on identity raises the issue of seeking perfection.

2. Perfection.

The concept of seeking perfection via genetic enhancement raises two critical issues: stewardship and naturalism versus transhumanism.

Stewardship.

Engaging the debate on stewardship in the context of enhancement is challenging.[36] Typically, we make moral assumptions such as the obligation of non-malfeasance to future generations.[37] Stewardship entails an obligation about many inter-related issues: the use of natural resources, culture and technology, preservation of the environment, natural resources, and oversight of the human gene pool.[38] Hence, stewardship obligations inevitably extend to future generations, both in a personal manner (impacting humanity) and in an impersonal manner (impacting the environment).[39] Additionally, the debate on seeking perfection via genetic enhancements involves justice, regarding human capabilities and the human life span.[40] Our current obligations towards future generations must be construed as a crucial matter of justice, [41] especially from the perspective of respecting human dignity.[42]

Naturalism versus Transhumanism.

The quest for perfection is not new to the human species. The core debate is over the distinction between naturalism and transhumanism. Naturalism can be construed as a legitimate form of human progress from the perspective of natural immanence and from the perspective of natural defects. The first point that clarifies the meaning of naturalism has to do with its relation to the concept of immanence. [43] This refers to an inherent dynamic within the human condition that considers human dignity to flourish by leaving human nature alone.[44] This means that the inner dynamism (immanence) of nature must be respected.[45] The second point that clarifies the meaning of naturalism is the capacity to improve on human defects. The dignity inherent in Naturalism does not prevent overcoming human defects.[46] One of the greatest difficulties for human nature is facing

up to it inherent defects.[47] Naturalism permits using technologies for prevention and treatment to overcome these inherent defects.[48]

In contrast, transhumanism seeks radical alterations of the human capacity to overcome human limitations. As mentioned previously, respecting the inner dynamism of nature to realize our human potential can change human nature.[49] However, transhumanism seeks to overcome all human limitations, disease, and frailties.[50] The hallmarks of transhumanism include enhancing appearance, increasing the capacities of human senses, advancing intelligence, increasing lifespan and alleviating the vulnerabilities of harm.[51] Additionally pursuing the excessive desires and wants of humanity,[52] all through enhancing the human capacity.[53] Transhumanism typically is associated with what is called post-humanity, emphasizing the radical change in a new form of humanity.[54] Inevitably, the agenda of transhumanism will have a significant impact on the idea of what is good,[55] correlating it with radical improvements of the human capacity.[56] Transhumanism contends that an improved world with superior human conditions can be achieved by not only enhancing the human capacity but also by radically overcoming human limitations.[57] In other words, human life in its current form is construed to be in the early phase of development,[58] with major achievements in human development to be achieved.[59]

Critics fear that the main consequences of transhumanism will lead to different reality of humanity called post-human.[60] The consequence exposes a dramatic inequality between current humanity and post-humanity.[61] The new being that is free from disease.[62] As a result, the argument against Transhumanism is that, in addition to compromising the meaning of human dignity, progress would be better targeted towards diminishing current

problems in humanity such as violent aggression.[63] A critical platform to advance the debate on enhancement and transhumanism is the technologies that are emerging with regard to germline modification, as discussed in the next major section.

II. Germline Genetic Modification.

The ethical debate on genetic enhancement in general leads to the more specific focus on genetic germline modification that requires examining two related perspectives, the religious and secular perspectives.

A. Religious Perspectives.

First, two mainstream religious perspectives of germline genetic modifications are represented in the views of the Roman Catholic Church and traditional Protestant Christianity.

1. Roman Catholicism.

The Roman Catholic views of germline genetic modification can be evaluated by what is permissible and prohibited.

Permissible.

The possibilities for germline modification will occur often in the context of prenatal diagnosis. The morality of prenatal diagnosis is permissible as long as there is adequate informed consent of the parents and appropriate precautions are taken to protect life and integrity of the embryo and mother. Additionally, the embryo and the mother should not be subjected to undue risk.[64] These conditions contain the core elements involved in research ethics.[65] Catholic theology is compatible with science, not in conflict with it. Where conflict exists science and theology must be reconsidered and evaluated.[66]

Two theological points need to be stressed. First, God as creator has imbued human beings with intelligence to share in his creative power. God, in giving humans that intelligence, expects humanity to improve the universe he has given us. Second, God has given us the mandate to be co-workers and exercise real creativity. We are not to be mere workers who execute his demands but true participants in bringing the world to completion. Catholic theology can constructively engage the evolutionary process.[67] In this context, modifying human genetics is directly tied to the person's good.[68] The Roman Catholic faith sets ethical limits to what humans can achieve, emphasizing that knowledge has consequences and thus may be problematic.[69] In other words, there are ethical limits for the action of human beings in pursuit of that knowledge.[70]

Prohibited.

Three components delineate a moral framework for prohibited areas regarding prenatal germline modification. First, because embryos are living human beings, any experimentation that is not therapeutic is illicit. Second, every individual human body has dignity thus it is not allowed to engage in cloning. And thirdly, personal dignity must be maintained, hence attempting to alter human chromosomes or genetic inheritance must not be allowed.[71] The central point in the Catholic Tradition is that human dignity must be protected.[72] Many other concerns must be addressed when discussing prenatal germline modification, such as privacy, justice, harm, long-term impact, and respect for the disabled.[73] From the Catholic perspective to be considered morally licit, germline genetic modification, even with a therapeutic goal, has disproportionate risks. These include significant loss of embryos and the potential for mishaps.[74]

2. Protestant Christianity.

Within traditional Protestant Christianity there are constraints and positive results in responding to questions regarding germline modification.

Permissible.

First, despite the constraints of traditional Protestant Christianity on germline genetic modification, there can be positive perspectives too. There is agreement that human nature was not created in its present form.[75] For example, germline modification can have a legitimate therapeutic goal or provide a possibility of restoring the human body.[76] Yet, while it can be permissible in general to implement curative medical interventions aimed at curing human disease, germline modifications go beyond this goal by impacting future generations.[77] One interesting possibility for germline modification is when it is adopted to increase resistance to deadly disease that impacts the human species.[78] Those diseases could be diagnosed and appropriate therapy implemented to forestall or even eliminate them.[79] In this scenario, it appears potentially acceptable insofar as it seeks to alleviate human suffering of current and future generations.[80]

These Catholic and Protestant perspectives share a sense of the paradox that science presents for religion. The theology of St. Paul in the Christian Scriptures identifies the paradox when he speaks of the "old self" being put to death and the "new self" coming into existence without the disappearance of the old body.[81] This paradox of transformation and improvement is nothing new for Christians.[82] Since the early Christian Church there has been virtually no dispute about the need for human improvement.[83] Rather, the debates have centered on how far humanity can be improved,[84] considering whether it is possible for us to improve ourselves or whether our

improvement is a result of grace.[85] The core Christian understandings of dignity and justice have guided engagement with technology and progress.[86] This sense of paradox between the "old self" and the "new self" that we should seek applies much more broadly than to technology, encompassing natural disasters and violence etc.[87] Also, the theologian Thomas Aquinas highlighted this paradox between the old and new, explaining that by the gift of grace human capacities be extended beyond their natural capability.[88] He understood human nature as being divided into first nature and second nature. The first nature is the part of us that we share with all mankind. Something we have little control over. Second nature varies and encapsulates various cultures as context-dependent. In this context, we can understand technology as enabling our natures to change, develop and improve.[89]

Prohibited.

Second, germline genetic modification has a number of constraints placed upon it.[90] Protestant Christianity is replete with cautionary tales limiting the embrace of acts that seem to defy natural limits.[91] Germline genetic modification cannot be used if it becomes a distraction from the primary goal of humans: union with God.[92] The use of germline modification cannot be used even if it is to benefit one's children through technology.[93] The alteration of human character as male and female is especially unacceptable.[94] Also, germline genetic modification is especially prohibited when it involves destroying embryos.[95] Furthermore, the view of the moral significance of early embryos by Protestantism has created different opinions about their moral status as persons.[96]

B. Secular Perspectives.

Second, the secular debate on germline genetic modification revolves around discussions on justice and the common good, and also implications for risk and safety.

1. Justice and Common Good.

Germline genetic modification raises significant concerns about social concerns and long- term impact.

Social Concerns.

Justice addresses social concerns related to germline modification.[97] If germline genetic modification could make medical and technological modifications to solve potential problems, those modifications could be justified.[98] But justice would require these solutions and improvements be made widely available.[99] Each must be given their due is the essence of justice.[100] There are different approaches to the discourse on justice, such as distributive, commutative, and rectificatory justice.[101] These stand separate from market pressures that can exacerbate the existing inequalities of society.[102] Across these different approaches to justice, a variety of strategies are adopted, such as the prohibition of innovations that would exacerbate injustices, the creation of innovations that would alleviate existing injustices, and the diffusion of innovations to avert unjust advantages.[103] Whatever approach to justice, or strategy to implement justice is adopted, they require that all of society should participate because of their communal impact.[104] The common good must prevail when addressing new genetic technologies. Equitable distribution of benefits is crucial for the common good,[105] and having solidarity with those most marginalized is indispensable.[106] The principle of solidarity describes social cohesion, respecting human rights and a communal commitment to order and responsibility.[107] This

notion of solidarity must pertain to individual, communities, and internationally.[108] Furthermore, the common good inevitably deals with global society,[109] especially when dealing with breakthroughs in germline genetic modification. Above all, there must be robust moral pressure against genetic advantages for only the wealthy.[110]

Long-term Impact.

The implications that germline genetic modifications have for justice and the common good highlight the long-term impact upon society in general. Germline genetic modification is fundamentally different from other genetic technology insofar as it will have a long-term impact. The potential for good and evil is great.[111] When medical and scientific communities tout genetic modification as a revolutionary tool to cure or eliminate disease or disabilities some may hear a paternalistic song that strikes fear and concern. A single-track focus on the so-called "technological imperative" can be disconcerting for many.[112] For example, human reproductive cloning would be highly controversial.[113] The embryo can become a means to an end when there is cloning of another human being.[114] A crucial question discussed earlier is whether this technology will exacerbate the injustices that already exist.[115] Insofar as the human system is a product of evolution, we must proceed extremely cautiously to avoid unpredictable consequences.[116] Future generations have to be given consideration; our social obligations are extensive.[117]

To address these long-term impacts that affect our common interests, regulation of germline genetic modification is indispensable. Because the genome is common property to all human beings, there is common heritage.[118] Germline modification should be regulated by international conventions on human rights. With regard to mobility and

migration, the whole species is at risk.[119] Minimum standards need to be provided to protect present and future generations. In consideration of common interest, transnational guidelines would have to support human dignity.[120] These regulations must especially focus upon avoiding harm.[121] The recommendations of The President's Council on Bioethics on Reproduction and Responsibility would command the respect and assent of most people. These recommendations include the need for the following: federal studies regarding the effects of these technologies, studies on the impact on health and well-being of women, studies on the use of reproductive genetic technologies and their effects on the children born utilizing these technologies, and strengthening the Fertility Clinic Success Rate and Certification Act.[122] Additionally, we must augment the oversight of societies and professional organizations, increase enforcement, and develop new ethical boundaries.[123] Finally, we need to implement legislation that would achieve the following: prohibit transferring embryos to nonhuman species, prohibit producing human-nonhuman embryos, prohibit the transfer of embryos for any purpose other than producing children, prohibit buying and selling embryos, and prevent the issuance of patents on human embryos or fetuses.[124] Citizen participation is paramount and would add to the social good in developing regulations of germline genetic modification technology.[125] An interdisciplinary approach is needed because of the complex interaction between genetics and ethics.[126]

However, in addition to the issue of justice and the common that focus upon the long-term impact on society, the extraordinary implications of germline modification for enhancement require close scrutiny of issues concerning risk and safety.[127]

2. Risks and Safety.

The risks involved in germline genetic modification raise two related ethical concerns: differing approaches and human-nonhuman chimera.

Differing Approaches.

The most dangerous aspects in genetic enhancement are the unintentional results that affect the germline. Being restricted to a limited scale can diminish risks.[128] Containment of genetic modification is easier in mammals than it has proven to be in the modification of plants.[129] In some cases, risks of unintentional genetic modification can be mitigated depending upon the genetic alteration.[130] However, unintentional genetic modification may not be reversible and may radically change the biology of what has been modified.[131] Different approaches to the risk reduction of unintentional germline modification are discussed in the literature, including total prohibition, implementing a risk reducing principle, or using cautionary heuristics.[132]

A cost-benefit calculation is a valuable tool in the debate over risk,[133] providing a way to articulate the considerations that need to be made in the evaluation of enhancements.[134] It has become increasingly helpful to apply principals of economic evaluation to effectively compare and analyze costs and outcomes of these genetic technologies.[135] Cost-benefit calculation can be used to help determine magnitude and probability in the identification of risk.[136] Only by determining the moral acceptability, affordability, and effectiveness of risk-reduction measures, can there be an evaluation of acceptable risk.[137] The ultimate goal is the reduction of risk to acceptable levels, even though eliminating them totally is not feasible. Evaluating the cost includes the benefits that would be lost and the costs we bear in trying to mitigate risk.[138]

Related to risk is the ethical concern of safety. The technology of germline genetic engineering makes safety a critical concern with regard to procreation. Germline engineering should pose no more risk than the ordinary process of conception and natural birth. Experiments in animals must assure the techniques implemented in humans do not cause any more problems than would a natural birth.[139] There must be a reasonable expectation that the human embryo would have a better chance of being free from the treated disease.[140] Also, at the time of implantation measures to minimize the dangers to the mother need to be resolved.[141] Hence, before embarking on germline engineering, long-term experience with somatic cell gene therapy needs to occur.[142] The support of women's reproductive rights are ethically relevant because of the significant consequences that could occur with process of genetically modified embryos.[143] The main focus must be upon safety to avoid untested and harmful therapies that could potentially compromise the mother.[144] In general, respect for individual and familial autonomy as well as reproductive rights of individuals and couples need to be kept in balance.[145] However, more specifically, the safety of the mother must be protected, especially regarding drugs and protocols used to stimulate ovulation and egg retrieval.[146]

Human-Nonhuman Chimera.

The religious and secular concerns of germline genetic modification can be illustrated in the discussion over the creation of and experiments on human-nonhuman chimeras. Core ethical concerns are shared in both religious and secular critiques. These can be categorized as concerns about the biological development of embryos for the purpose of creating chimeras.[147] This technology raises serious concerns regarding the moral status of those embryos, all of which are eventually destroyed.[148] Respect for the

moral status of embryos cannot be foregone even for the noble cause of investigating the potential for disease crossing species barriers.[149] In addition, animal welfare and animal rights need to be considered in the enterprise of creating these chimeras.[150] It can be argued that all living things have interests predicated in biology and to circumvent those interests is morally wrong.[151] In this regard, there needs to be a middle ground regarding care for and utilization of animals in research, most especially in cross-species experiments.[152] These are fundamental concerns that need to be explored in depth.[153] By combining human and nonhuman tissue, the potential to hinder both from fulfilling their purpose would be wrong.[154]

Above all, the denigration of human dignity would result from creating human-nonhuman chimera;[155] the concept of human dignity is crucial for evaluating the morality of these new genetic technologies.[156] The dignity of personhood is widely recognized as an individual of rational nature: whether that definition could pertain to chimeras is of crucial concern.[157] To natural law theorists (such as adopted in religious traditions like Catholicism), the order of nature has a standardizing force, thereby making it morally wrong to alter a human being's nature (such as embryo development),[158] including its basic functioning and capacities.[159]

The previous sections on genetic enhancement and germline genetic modification delineate the ethical landscape for evaluating new genetic technologies that will impact future generations. Two recent technologies have emerged that are now considered in further detail: mitochondrial DNA technology and gene editing technology with CRISPR.

III. Mitochondrial DNA.

The previous sections on genetic enhancement, and germline genetic modification delineate the ethical landscape for evaluating new genetic technologies that will impact future generations. Two recent technologies have emerged that are now considered in further detail: mitochondrial DNA and gene editing technology with CRISPR.

To discuss the ethics of mitochondrial DNA, the pivotal ethical topics require examining two related topics: the science of mitochondrial DNA and the ethical, social, and policy considerations.

A. Science of Mitochondrial DNA.

First, to understand the ethical debate on mitochondrial DNA, a discussion must address human reproduction as well as mitochondrial DNA biology and the mitochondrial DNA diseases and research.

1. Human Reproduction and Mitochondrial DNA Biology.

Basic fundamentals of human reproduction and mitochondrial DNA science need to be discussed.

Reproduction Basics.

Some fundamental concepts of human reproduction are the foundational cells involved in human reproduction are gametes. Fusion of an egg and a sperm cell creating a zygote is the first step in human reproduction.[160] At this early stage, the zygote is made up of both male and female pronuclei. The first replication of the pronuclear genetic material occurs prior to the nuclear membrane dissolving. The two-cell embryo is formed after the male and female genetic materials are fused forming the two-cell embryo each cell having equal complements of genetic and cytoplasmic material.[161] Two distinct cells

(somatic and germline cells) are derived from the embryo. Somatic cells form all the cell and tissue types while germline cells develop into either male spermatozoa or female oocytes. Germline cells make up the germ cell lineages.[162]

Mitochondrial Science.

Mitochondria are in nearly all cell types. The general role is in regulating cellular energy. The role includes production of cellular energy, regulating cellular metabolism, and assisting in subordination of programed cell death.[163] Mitochondria were once free-swimming bacteria that took up residence in another cell. They were very efficient at harvesting energy by burning oxygen.[164] The mitochondria are constantly swimming within cells in the body retaining their own genome; these are the vestiges of years of their evolution.[165] The mitochondria's primary function is in the production of the majority of energy needed to fuel cellular processes. They are often referred to as the powerhouse cells. Mitochondria are critically important by providing energy requirements for muscle and brain cells, users of high-energy demands. The mitochondria serve as regulators of many cellular metabolic functions and help maintain proper intercellular balance.[166] Mitochondria also contain the ability to convert fats, proteins, and carbohydrates into intermediates that directly impact the respiratory chain.

Mitochondria have their own genome containing mitochondrial DNA that in turn has some commonalities with nuclear DNA but differ in many ways.[167] They differ in their genome structure, mitochondrial are circular while the nuclear are linear. The mitochondrial has over 100,000 copies of the genome in each mature cell, while the nuclear has only two. In the number of DNA base pairs, mitochondrial has over 16,000 while nuclear has over three billion.[168] Another unique feature of mitochondrial genetics

is each cell, tissue, and person contains more than one mitochondrial DNA. While it is agreed-upon that mitochondrial DNA is essential in cellular energy production, it is generally agreed that nuclear DNA's predominant function is in the characteristics of anatomy, physiology, and personality. In humans, mitochondrial DNA is inherited solely from the mother and only females pass their mitochondrial DNA to offspring both male and female. However, male mitochondrial DNA does not pass on to future generations.[169]

2. Mitochondrial DNA Diseases and Research.

Mitochondrial maladies and various techniques of research of mitochondrial DNA will be discussed in this section.

Mitochondrial Maladies.

The diseases of mitochondrial DNA are very similar, manifesting themselves in the respiratory chain activity. Because of reduced cellular energy production they manifest themselves in the organs of the highest energy demand. To date, there is no approved treatment or cure only supportive and palliative care. These resultant diseases are because of the defects in nuclear DNA or mitochondrial DNA.[170] Because of dual genomic control the respiratory chain diseases are result of nuclear DNA or mitochondrial DNA mutations.[171] Some of the maternally inherited mitochondrial DNA diseases are Leigh syndrome; mitochondrial encephalomyopathy, lactic acidosis, and stroke-like episodes; myoclonic epilepsy with ragged-red fibers; neuropathy, ataxia, and retinitis pigmentosa; maternally inherited diabetes and deafness; maternally inherited Leigh syndrome; and Leber hereditary optic neuropathy.[172] These diseases range from very mild to severely debilitating or fatal. Their onset can be in early life or manifest

themselves in adulthood. Generally the mitochondrial diseases tend to have later onset and milder symptoms compared to nuclear DNA diseases that typically are earlier in life and often more severe.[173] It is estimated that 1 in 5000 people have a pathogenic mitochondrial mutation.[174] Further extrapolation estimates that 778 children are born per year in the US from women at risk of transmitting mitochondrial DNA disease.[175] Treatment of the diseases is very difficult, because of (1) the heterogeneity and (2) the lack of success of delivering treatments into the mitochondria.[176]

Various Techniques

Research of mitochondrial DNA diseases has led to gene editing of somatic cells and while having great promise also has had limited success in humans.[177] By using an investigational technique, heteroplasmy shift, which selectively targets and degrades pathogenic mitochondrial DNA mutations has seemed to offer efficacy in animal studies but has not yet been utilized in humans.[178] The real advantage with this technique, it would not require the use of genetic material from a second woman.[179] Another powerful technique is preimplantation genetic diagnosis, even though it has had limited studies it does show significant potential. Its limitation is that the technique involves selection of an embryo with the least amount of detectable heteroplasmy but does not eliminate the risk of transmitting the disease to offspring.[180]

To date, none of these options give prospective mothers peace of mind that their children may not develop mitochondrial DNA diseases.[181] Mitochondrial replacement techniques are being investigated for their benefits. Two of these techniques are maternal spindle transfer and pro-nuclear transfer. Both of these techniques involve the restructuring of the oocyte by replacing the mutated mitochondrial DNA with a donors

nonpathogenic mitochondrial DNA.[182] There is an important difference between these two techniques. Maternal spindle transfer entails removal of the nuclear DNA from the mother's oocyte, which is then infused with a donor's nonpathogenic mitochondrial DNA oocyte. The newly reconstructed oocyte is then fertilized and cultured in vitro to the blastocyst stage.[183] The combined embryo would then be tested for abnormalities, heteroplasmy levels, and sex selection.[184] With pro-nuclear transfer, the nuclear DNA is transferred between fertilized oocytes prior to fusion of the pronuclei. The pronuclei of the male and female are removed from the zygote and fused to the enucleated zygote of the sperm providers' sperm and an oocyte of provided by an unintended mother. Again, the newly constructed oocyte would be cultured to blastocyst stage, and then would undergo genetic testing.[185]

A third technique, polar body transfer, has been proposed but there has been only limited investigation regarding its ability to prevent mitochondrial DNA disease transmission; hence it was not included in the Institute of Medicine's Report. Similarly other methods of preventing the transmission of mitochondrial diseases that are not under United States Food and Drug Administration consideration (cytoplasm transfer, somatic cell nuclear transfer, and embryo cell nuclear transfer, and germinal vesicle transfer) were not included in the Institute of Medicine's Report.[186]

B. Ethical, Social, and Policy Considerations.

Second, an understanding of the science of mitochondrial DNA sets the stage for addressing ethical, social, and policy considerations. These considerations are in large part addressed in discussions of unintended consequences and the recommendations of the Institute of Medicine.

1. Unintended Consequences

Heteroplasmy, mitochondrial DNA bottleneck, and mitochondrial evolution will be discussed in evaluating unknowns and predicting impact.

Evaluating Unknowns

Three unique considerations have to be made in mitochondrial genetics to effectively evaluate unknowns and unintended consequences in research. They are heteroplasmy, mitochondrial DNA bottleneck, and mitochondrial evolutionary theory.[187] Because of these complexities there is an unpredictable nature about mitochondrial genetics that make the ability to predict preclinical studies with certainty and safety very difficult.[188]

Heteroplasmy is a state where more than one type of mitochondrial DNA genotype is contained in a cell, tissue, or individual. When a threshold effect occurs, cells containing mutations display dysfunction only when a certain level mitochondrial DNA transmission is reached.[189] Heteroplasmy levels can fluctuate at different rates because of the shifts in proportion of pathogenic mitochondrial DNA transmission. The pathogenic mitochondrial DNA molecules can be distributed unequally into daughter cells shifting heteroplasmy levels.[190] Mitochondrial DNA bottleneck can occur during oocyte development. Then only a fraction of the original pool of the mitochondrial DNA molecules is divided into daughter oocytes.[191] Because of this bottleneck, the number of mitochondrial DNA molecules can be reduced from nearly 100,000 to as few as 10.[192]

Predicting Impact

Rapid changes in the level of mitochondrial DNA mutations can occur from one generation to the next thus impacting the mitochondrial DNA evolution. All these factors

add to the complexity of determining risks.[193] Potential incompatibility of artificially combined nuclear and mitochondrial genomes are of major concern.[194] Studies have shown that certain genome backgrounds are often only compatible with each other and incompatible pairings are often selected unknowingly.[195] Another problem is the mitochondrial DNA could accumulate mutations that could have a negative impact on males and a positive impact on females.[196] A potential uncertainty is inadvertent physical damage to the reconstructed oocyte or zygote.[197] The complexity of mitochondrial genetics makes predicting behavior of the mitochondrial DNA challenging and filled with uncertainty. Thus predicting the efficacy and safety because of uncertainties and unknowns is challenging. To assess the benefit and risk a thorough understanding of the unknowns is paramount.[198]

2. Institute of Medicine Recommendations.

In this section, impact considerations and criteria for expansion will be delineated.

Impact Considerations.

The Institute of Medicine's Report concluded that with adherence to sets of conditions, the clinical investigation of mitochondrial replacement techniques should be allowed to move forward. The following ethical, social, and policy recommendations were made in the Institute of Medicine's Report that has significant ethical implications for discussions about the ethics of germline modification upon which this essay is focused.

Mitochondrial replacement techniques should be considered if the following conditions are met: (1) safety must be established and risks to all parties must be minimized, especially to future children; (2) the likelihood of success must be evident;

(3) investigations must be limited to women who are risk of transmitting severe mitochondrial DNA diseases; (4) risk should be minimized to alleviate adverse health for pregnant mother and fetus; (5) investigators and centers have to have demonstrated expertise for this technology; (6) investigations should be limited to male embryos for intrauterine transfer; and (7) every possible risk of mitochondrial DNA-nuclear DNA incompatibility needs to be mitigated.[199]

Ethical standards developed by the United States National Academies of Science, Engineering, and Medicine, the United States National Institute of Health, and the International Society for Stem Cell Research must be adhered to with regard to human embryos. Nonviable embryos must not be used in the preclinical research.[200] Also, clinical investigations must follow these principles and practices: (1) the future well-being as a result of mitochondrial replacement techniques must be given priority in balancing benefits and risks; (2) standardization of protocols must be of highest priority to the minimize the number of variables and accommodate pooling of information; (3) data from all research must be incorporated to improve the quality of assessment; and (4) long-term studies regarding psychological and social effects on children born as a result of mitochondrial replacement techniques have to be collected.[201]

Criteria for Expansion.

If success in transferring male embryos is demonstrated then consideration should be given to include the transfer of female embryos if: safety and efficacy using male cohorts has to be demonstrated, regardless of the time to collect this evidence; animal research has had to demonstrate intergenerational safety and efficacy; and there is a

predicated consistency of decisions that are compatible with public and scientific deliberations.[202]

Due to the unusual aspects of mitochondrial replacement techniques research, special attention must be given to communicating to research participants. Participants who provide gametes, the informed consent process must include: (1) the procedures anticipated in any ethical, social, and policy considerations; (2) appropriate compensation; (3) management of unused eggs; (4) the embryos; and (5) provisions for contact of those who provided gametes and children born as a result. For the parents, the informed consent process must include: (1) focus on the health and well-being of children born of the research protocol; (2) alternative means of begetting children that avoid transmittal of mitochondrial DNA disease; (3) discussion of restrictions on access to embryos created; (4) incorporating prenatal genetic testing; (5) the insistence on long-term follow-up regarding any child born as a result of these protocols; and (6) maintaining patient privacy. For the children born, assent and eventual consent must be gleaned for monitoring and research procedures.[203]

The United States Food and Drug Administration's review, approval, and subsequent marketing of mitochondrial replacement techniques must incorporate the following elements: (1) transparency that maximizes public sharing of information; (2) public engagement through the involvement of relevant stakeholders; (3) partnership with other regulatory authorities in aiding the assessment of benefits and risks; (4) maximization of data quality through cross-referencing and pooling; (5) circumscribed use by limiting the use of the technology to individuals and settings for which it is approved; and (6) long-term follow-up with periodic review must be a requirement.[204]

IV. Gene Editing with Clustered-Interspaced Short Palindromic Repeats (CRISPR).

Closely related to the mitochondrial DNA ethical discussion is the debate on CRISPR. This is gene editing technique targeting and modifying DNA. The pivotal ethical discussions on CRISPR address two related topics, the science of genome editing and the ethical, social, and religious concerns.

A. Science of Gene Editing with CRISPR.

First, to appreciate the science of genome editing with CRISPR requires understanding of its history and its methodology.

1. History.

An historical overview of CRISPR from its original roots to current status will be discussed.

Historical Overview.

The history of CRISPR has its original roots in the new era for biology with the development of recombinant DNA technology in 1970s. The manipulation of DNA molecules was first accomplished thus gaining the ability to study and develop genes. The genes were harnessed to develop novel medicine and biotechnology.[205] Genome engineering is very broad term referring to the process of making specific modifications to the genome. Innovative techniques have been developed for altering genetic sequences.[206] Early gene therapy trials were very successful in the curing of 17 children with severe immunodeficiencies.[207] Unfortunately, four children died of leukemia-like symptoms attributed to gene delivery, inserting into an unpredictable location within the chromosome. Misplaced insertion can occur in the human genome that regulates cell growth and division resulting in uncontrolled growth of cells.[208] In another gene therapy

trial, a patient died as a result of an immunological response of the material used to deliver the corrected gene. In both these cases, the role of the delivery method contributed significantly to the adverse outcomes.[209] CRISPR itself was discovered in Japan where they were the first to observe clustered-interspaced short palindromic repeats in the DNA of bacteria in 1987.[210] In an attempt to study a protein-encoding gene in Escherichia coli, researchers observed short, repeating, palindromic DNA sequences separated by short, nonrepeating, spacer DNA sequences.[211]

Current Status

Current development began in 2010 when the intricate detail of the mechanism where bacteria are infected by other microorganisms, called bacteriophages or phages were explained by two research groups of the University of California Berkeley and Umea University in Sweden.[212] The CRISPR system recognizes specific patterns of DNA from the foreign invaders and decapitates them by cutting the invaders DNA into pieces. The way that the bacteria targets specific DNA and cleaves it gave scientists a hint of its potential in other applications.[213] In 2013, two research groups from Massachusetts Institute of Technology and Harvard University successfully modified this basic mechanism and turned it into a powerful tool that can now cut human genomic DNA at any desired location.[214] For example, in Summer 2016, China pioneered the first human CRISPR clinical trials.[215]

2. Methodology.

Tools for genome editing and the potential for CRISPR technology will be engaged in this section.

Tools for Genome Editing.

The methodology for genome editing was by targeted molecular machines. These machines have been used as tools for many years.[216] Researchers have developed many innovative techniques for altering genes since the first modifications were made. Recently, breakthroughs using Zinc finger nucleases and transcriptional activator-like effector nucleases have significantly reduced cost and complexity in targeting changes in living cells but CRISPR is by far the easiest to use. [217] Experts believe these advances could have wide-ranging clinical applications with the potential to prevent or cure a variety of diseases.[218] The newest of the gene editing technology is CRISPR. It was adapted from an immune system found in prokaryotes.[219] It has been established that bacteria have evolved with a defense mechanism against viruses. When bacteria encounter an invading source of DNA, segments of the foreign DNA can be copied and incorporated into their genome as spacers between the short DNA repeats in CRISPR.[220] With a piece of the invading DNA it can be copied into the host genome, which serves as a genomic memory of invading pathogens. These spacers enhance the bacteria's immune response by providing a template for RNA molecules to quickly identify and target the same DNA sequence in the event of future viral infections.[221] If the RNA molecules recognize the incoming sequence of foreign DNA, they guide the CRISPR complex to that sequence. At that point the bacteria's Cas proteins, which are specialized for cutting DNA, splice and disable the invading gene.[222] The CRISPR system is unique from other technologies requiring no protein engineering, only synthesis. The simplicity of this technology drastically reduces the time for conducting genome experiments.[223]

Potential.

Since the first recorded use of CRISPR technology in January 2013, it has shown significant progress in demonstrating therapeutic potential.[224] Because of the simplicity and affordability of the system it makes itself accessible to researchers. In recent in vivo studies in primate embryos, it has shown compelling progress that will expedite rapid advancement toward clinical trials.[225] This technology has shown great promise in several monogenetic disorders such as sickle cell, cystic fibrosis, and even showing potential in the prevention of coronary heart disease.[226] Additionally, researchers have explored many different applications including genetically modified crops, eradicating viruses, screening for cancer genes, and genome engineering.[227]

B. Ethical, Social, and Religious Concerns.

Second, the concerns about CRISPR technology need to be discussed from the perspective of social and ethical dimensions as well as from the religious perspective.

1. Ethical and Social Concerns.

In this section, the concerns about CRISPR technology's impact will be discussed from the perspective of social and ethical dimensions and possible regulation of the technology.

Impact.

The concerns regarding the social and ethical implications of CRISPR "reprogramming DNA" have similar concerns to those of genetic manipulation. Most notable of the concerns are passing on to subsequent generations deleterious impacts to the human genome.[228] Clinical trials of CRISPR gene editing system have not been implemented on the human somatic genes but it has been used to create genetically

engineered mosquitoes. These genetically engineered mosquitoes are no longer capable of transmitting malaria thus possibly eliminating the disease. To increase the efficiency and improved targeting, significant work remains to prove safety and efficiency.[229] Two applications, both alluded to, that are most concerning about the CRISPR applications are the edits of human reproductive tissue and the generation of and release in the wild of transgenic organisms that are capable of continuing these edits.[230] Any edits made would be made without consent of the any individual who carries them in the editing of the genomes of other species is fraught with concern regarding irreversible ecological alterations. CRISPR needs three things to work: DNA encoding the genome cutting enzyme, DNA encoding the guide RNA, and DNA that serves as a repairable template.[231] Gene editing for targeting somatic genes is imminent for application in embryos and gametes but the technology is most likely useful in treating monogenic diseases rather than polygenic ones. Before this technology can be utilized for germline modification, significant knowledge needs to be gained regarding human genetic interaction and the interplay between diseases.[232]

Regulations.

Regulation of this technology is looming because of the potential for exploitation in non-therapeutic uses, off target modifications, and embryonic screening.[233] Because of the potential of permanent changes in the human genome, changes from intellect to physical qualities, there has been growing support for a ban on germline modification for reproductive purposes.[234] Due to the lack of societal consensus and safety concerns it would be irresponsible to try to produce human pregnancy from the modified germ cells or embryos.[235] This takes on new urgency especially in light of Chinese work in

nonviable human embryos using the CRISPR technology.[236] Three phases of regulation are being proposed: preclinical research, clinical trials, and post approval distribution. To ensure safety and ethical guidelines, financial and regulatory checkpoints would be developed.[237] Prior to research a complete internal review board approval would be mandatory. Transitioning from research, the clinical to commercialization, government agencies such as United States Food and Drug Administration or the European Medicines Agency would ensure safety, and quality. Sufficient guidelines would need to be in place.[238]

2. Religious Issues.

Discussed in this section are some of the religious concerns such as dignity and the unitive procreative connection.

Dignity.

The dignity imputed to human beings is the major religious concern in the context of genetically editing the human genome with the CRISPR technology. With human genome editing a distinction must be made between editing for therapeutic purposes and enhancement to augment human capacities. The intervention must be effective and reasonably safe. The benefit must outweigh any possible risks.[239] The effort to alter the germline therapeutically could be acceptable if respect for human dignity offspring is maintained.[240]

Unitive and Procreative Connection.

Also, the unitive and procreative aspects of the marital act must be maintained.[241] In the Catholic Church's Apostolic Exhortation "Familiaris Consortio," it is stated that the conjugal act is a sign and language. If the internal commitment to conjugal love is

revoked, the act itself is counterfeited and lacks moral dignity.[242] In principle, the Catholic Church supports research insofar as God has entrusted nature to our stewardship. This research within reasonable limits is permissible especially when it has the potential for saving human lives.[243]

The ethics of enhancement via germline genetic modification delineates the general ethical landscape for assessing specific technologies that emerge, such as mitochondrial DNA and CRISPR techniques. First, the pivotal ethical issues related to genetic enhancement are influencing human progress that includes human development and human nature. Additionally, in a discussion of influencing future generations, moral identity and perfection must be included. Second, the pivotal ethical issues related to germline genetic modification dealt with concerns that engage religious and secular discourse. Roman Catholicism and traditional Protestant Christianity's concerns were explored. The major secular concerns, justice, common good, risk and safety (with human-nonhuman chimeras being an illustration of the debate), have been considered.

Then two emerging technologies were examined to illustrate how the general ethical argument on germline enhancement can be applied to particular techniques: mitochondrial DNA technology and gene editing technology with CRISPR. To discuss the ethics of mitochondrial DNA technology, the pivotal ethical topics were organized into two categories, the science of mitochondrial DNA and the accompanying ethical, social, and policy considerations: the discussion of mitochondrial DNA science considered human reproduction and the biology of mitochondrial DNA as well as the diseases and research potential of mitochondrial DNA; the ethical, social, and policy considerations focused upon unintended consequences and the expert recommendations

of the Institute of Medicine. To discuss CRISPR gene editing technique that modifies DNA, the pivotal ethical topics were organized into two categories, the science of genome editing and the accompanying ethical, social, and religious concerns: the science of CRISPR was explained from the perspectives of its history and methodology; and the ethical and social concerns were connected with religious concerns about clustered-interspaced short palindromic repeats technology.

This chapter has explored the ethical debates on the emerging regenerative technologies. The next chapter moves to address technological issues that arise at the end of life.

V. Critique Based on the Ethical and Religious Directives.

As mentioned in Chapters 3 and 4, the Catholic Tradition's use of Natural Law has two general approaches. The first approach focuses on the universal aspect of human nature. This approach is typically associated with the settled Catholic teaching on morality. The second approach focuses on the person, presenting a dynamic and historical view of the human condition as contributors to God's creation.[244] This approach is typically associated with the Principle of Double Effect to apply traditional Church teaching in a flexible manner to changing circumstances. Arising from these two approaches to Natural Law, a third approach has emerged combining the nature-oriented and person-oriented approaches to new dilemmas regarding emerging technologies that may require doctrinal development in Catholic teaching.

In the conclusion of each applied chapter, a critique based on the Ethical and Religious Directives is presented regarding the main topics of the chapter. The critique adopts the above approaches to identify three distinct categories as follows. Category A

deals with settled issues in Church Teaching reflecting the Nature Approach to Natural Law. Category B deals with the controversial issues eligible for using the Principle of Double Effect reflecting the Personal Approach to Natural Law. Category C deals with issues requiring doctrinal development in Catholic teaching to address new dilemmas regarding emerging technologies.

The following analysis applies this threefold critique to the topics discussed in this chapter on regenerative technology. Each main section is discussed in turn.

Section I. Genetic Enhancement.

This section discussed ethical meaning of human nature and this is settled Catholic teaching in a manner that opposes genetic enhancement (Category A). Catholic teaching opposes genetic enhancement based on the nature approach to Natural Law. This argument resists the so-called temptation to seek perfection.[245]

The manipulation of the human genome is not new to Catholic teaching. Whether it is Francis Galton's concept of biometry or Gregor Mendel's study of the gene, the Church has been in dialogue to garner the good of genomic science and avoiding any harm.[246] Notably, the Catholic Church led opposition to eugenic efforts in the United States during the early 1900s. In spite of the history of eugenics, there is renewed interest in new technologies that could impact the human species in a eugenics manner.[247]

Another topic in this section dealt specifically with genetic interventions that deal with disease. There is settled Catholic teaching that permits any medical intervention (including genetic intervention) to overcome disease in individual patients (Category A).

However, a crucial distinction must be made between therapeutic genetic changes and genetic enhancement. Therapeutic changes are ones that aid a person to return to

"normal functioning" status.[248] Here, increasing our health could lead to increased longevity. The goal here is not perfection but overcoming disease that contributes to fulfilling human capacity.[249]

Another topic in this section deals with supernormal enhancements to seek perfection, especially occurring via genetic manipulation of the germline. This is forbidden now, and would require doctrinal development to examine future species related genetic enhancements (Category C). The reason for this Catholic stance is that germline genetic enhancement would be deleterious to humanity because of the unknown factors being passed on to future generations and the potential abuse of the most vulnerable in our societies.[250] Manipulation for enhancement could promote a eugenic mentality. This enhancement could attach social stigma to people who lack certain qualities while giving advantages to others who enjoy qualities that are appreciated by certain cultures. Impact upon the common good would be expected because of the favoring the will of some over the freedom of others.[251]

Section II. Germline Genetic Modification.

Continuing this theme of genetic enhancement, the section discussed germline genetic modification as being prohibited in Catholic teaching. Future developments here would require doctrinal development (Category C).

Two perspectives contribute to this Catholic prohibition of genetic modification. First, the embryo has inherent dignity; hence any genetic experimentation that is not therapeutic is illicit. Second, every individual human being has dignity; hence any germline genetic modification that could compromise this dignity is not allowed. That is, personal dignity must be maintained hence attempting to alter genetic inheritance is

forbidden.[252] Within the Catholic Tradition, the main objective when considering germline genetic modification is the protection of human dignity of individuals and the species.[253]

In this section, human-nonhuman chimeras were also discussed. These are forbidden and future technologies arising from them would require doctrinal development in Catholic teaching (Category C).

The basic ethical concern here deals with the ethical status of a chimera. Because of unique human dignity, moral limits need to be discussed. With a potential benefit to humanity, the Catholic Church in principle does not object to the respectful use of animals in research. However, research in human/animal chimeras raises significant ethical and legal concerns around the compromise of the human embryo and the resulting ethical status of a human/animal chimera for research purposes (even if the chimera is destroyed after the development of primitive streak as required by regulation).[254]

Although, the Congregation for the Doctrine of Faith has not addressed the creation of chimeras that can be used for 'hybrid cloning' directly, the basic issue of identity makes the research morally and ethically unacceptable.[255]

Section III. Mitochondrial DNA.

This section discussed mitochondria (the structures within cells that convert the energy from food into a form that cells can use). Mitochondrial DNA diseases have no cure, and are progressive and often life-threatening.[256] The basic concern with mitochondrial DNA transplants to avoid transmitting disease is that the technology involves a third parent's DNA. This is construed in Catholic teaching as compromising the unitive/procreative bond of marriage and is forbidden; to accept any new technologies

based on this to the would require doctrinal development in Catholic teaching (Category C).

These types of intervention and mitochondrial DNA transplants are ethically problematic and are addressed in the Ethical and Religious Directives when Directives #50 and #51 discuss prenatal diagnosis and non-therapeutic experiments.[257]

> Prenatal diagnosis is permitted when the procedure does not threaten the life or physical integrity of the unborn child or the mother and does not subject them to disproportionate risks; when the diagnosis can provide information to guide preventative care for the mother or pre- or postnatal care for the child; and when the parents, or at least the mother, give free and informed consent. Prenatal diagnosis is not permitted when undertaken with the intention of aborting an unborn child with a serious defect. (Directive #50)

> Nontherapeutic experiments on a living embryo or fetus are not permitted, even with the consent of the parents. Therapeutic experiments are permitted for a proportionate reason with the free and informed consent of the parents or, if the father cannot be contacted, at least of the mother. Medical research that will not harm the life or physical integrity of an unborn child is permitted with parental consent. (Directive #51)

The complicated nature of mitochondrial genetics makes anticipating behavior of the mitochondrial DNA filled with uncertainty. Thus predicting the

efficacy and safety is challenging. To assess the benefit and risk, a thorough understanding of the unknowns is paramount before any technology is implemented.[258]

Section IV. Gene Editing with CRISPR.

This section discussed gene editing with CRISPR. This fast developing technology could be permissible in Catholic teaching when applied to somatic cell (not germline) therapies using the Principle of Double Effect (Category B).

Studies have shown that it may be possible to delete or disable genes in an embryo that may be carrying life-limiting abnormalities.[259] Many consider CRISPR research as experimental and not therapeutic, arguing that a moratorium is needed.[260] There are multiple moral quandaries created by this technology, which has been endorsed by the Institute of Medicine.[261]

Furthermore, the distinction between therapy and enhancement is being recalibrated by some as a distinction between therapy and non-therapy. Based on burden-benefit analysis using the Principle of Double Effect, CRISPR technology could be justified to overcome disease in individual patients. However, Catholic teaching requires that we need "reasonable boundaries to distinguish genetic interventions that preserve and promote human dignity from those that may endanger and marginalize it."[262]

Germline genetic modifications that impact the germline or inheritable change at the level of the egg or sperm that could be passed to future generations is currently problematic in Catholic teaching. Procedures used at the somatic cell level for therapeutic purposes can be morally licit. The moral evaluation of the germline cell therapy is different. The risks connected to any genetic manipulation are considerable and yet not

fully controllable. Currently, Catholic teaching holds that it is not morally permissible to act in any way that could cause harm to the resulting progeny. The Church refers to this manipulation as "the human genetic patrimony."[263] That is, to the extent that CRISPR technology could change the human germline (as typically will occur with embryos) it is forbidden, and approval of developments of this technology would require doctrinal development in Catholic teaching (Category C).

In sum, the threefold ethical critique based on the Ethical and Religious Directives has been applied to the topics discussed in the main sections of the chapter. This threefold critique is applied at the end of the next applied chapter.

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Chapter 6. On Death and Dying.

Throughout history, the attitudes of death and dying have transformed gradually, shifting focus from the dying and their families to the role of the physician and the health care team. As a result, the dying process has become rife with ethical dilemmas. To adequately discuss death and dying requires examining three related topics: changing attitudes to death and dying, the meaning of medical futility, and the withdrawal of life-sustaining treatment.

I. Changing Attitudes towards Death and Dying.

Death is the final journey all must take. To discuss the changing attitudes towards death and dying, two areas elicit attention, the contemporary characteristics of death and dying and related philosophical approaches.

A. Characteristics.

First, contemporary characteristics of death and dying can be revealed in discussions about the locus of control and about accompanying rituals.

1. Locus of Control

Throughout history, the locus of control (the sense of authority over a situation or experience) gradually shifts from the dying and his family to a physician and health care team. To adequately engage the locus of control, a tame death and prolonging life must be discussed.

Tame Death

Death is a final journey all must take. Like an unwanted visitor, death is sometimes a kind act of nature. At other times, death is not kind when it is the result of violence. Even though death can be one of the most painful encounters one can

experience, all remain morbidly curious about it. Society had moved from the time when individuals were able to listen to their inner voices about impending death accordingly death was not a struggle, and people usually passed away without fear. Death was a part of life. Aries refers to this perspective as "tamed death," or one that comes with natural warning signs.[1] A long lingering death was very unusual. People typically died of disease with rapid onset and a quick end. People were usually forewarned, and that forewarning came through natural signs and inner convictions.[2]

Unfortunately, the current mandate is one in which individuals (including family members and doctors) make every effort to prolong the death process under the guise of prolonging life. No longer do individuals allow themselves to hear the voice of death, to acknowledge the voice of death, nor to accept the voice of death. Every conceivable tool, technological advancement, and chemical medication to prolong life is provided. In reality, death is merely being postponed. This change in attitude towards death over the millennia is unfortunate and deplorable. This dissertation examines various health care philosophical tenets and their loci of control: physician-centered paternalism and beneficence as well as autonomy, which are patient-centered. Additionally, the moral tradition of the sanctity of life within a historical context of changing attitudes towards death and dying will be discussed.

Prolonging Life.

Before the 12th century, there was a familiar resignation that all would die. At that point, things began to change: the awareness of self and death took on a new meaning: "one's own death."[3] Subtly over time, death became very personal and was viewed as a natural event. By the 1800s, the locus of control shifted from the dying person to the

survivors of the dying. Now the survivors of the dead found it difficult to deal with the death of another person. Death of self was not as feared as much as a death of another.[4]

By the 1900s, a different sentiment emerged about death: it must be avoided at all cost. In the midst of a happy life, there was no room for death because life is always happy or should always seem so. This pall of death and the sadness associated with it was viewed as unacceptable to family members and the greater society as a whole.[5]

The locus of control shifted once again in the 1930s to the 1950s to physicians and the health care team. Once considered a shelter for the poor, the hospital became the place for everyone to receive care that could no longer be provided at home. The technology of the day, even rudimentary devices, was available only in hospitals and they logically became the place where one would struggle against death. In this period, if one died in the hospital, the physician failed in healing rather than death being seen as a part of nature. Death became a technical phenomenon.[6] For centuries, death was the jurisdiction of the dying individual and his survivors. Only recently and still somewhat today, the locus of control is the physician and the hospital team, who are the masters of death.

2. Rituals.

The locus of control of death regarding the use of medical technology needs to be situated within a broader context that respects rituals around death. To appreciate these rituals it can help to be attentive to the history and evolution of rituals around death.

Historical Overview.

As the locus of control shifted over the centuries, so too did the rituals of death. The death occurred typically in bed. The pre-death rituals were organized by and presided

over by the dying person himself. Everyone knew the protocol. Ceremonially, simplicity of the rituals of dying was accepted and carried out.[7] The "tamed death" came to an end due to a combination of both cultural and religious changes and the rise of scientific medicine. In the 1700s, life expectancy had begun to shift and the view of death as well. By the 1800s, the rituals of mourning and loved ones being taken away became known as a communal evil. At that time, death became a more segregated personal event. By the late 1900s, death was taken out of the hands of families and put in the hands of doctors and medical institutions. This marked the beginning of the 'big lie' or the hiding of imminent death. Most believed that technology could change nature giving birth to the belief that death had been eliminated. Technology had replaced nature and the elimination of death. A resigned acceptance of death was lost in favor of the medical management of death.[8]

Evolution.

Other noticeable changes were the custom of mourning and the purpose of a will. From the end of the Middle Ages to the 1700s, mourning took on a double purpose. It served as a period of sorrow out of respect for the family who experienced the death of a loved one. However, mourning allowed for the dissipation of grief.[9] Once when too much emotion was displayed by mourners and viewed as mental instability or bad manners, grief soon became more reserved. Outward signs and customs for death likewise evolved over the centuries. The wearing of dark clothes by family members and mourners gave way to daily attire; no one dressed any differently because of the death of a family member. Another notable change was that children used to be allowed around the deathbed, in full participation with the dying process. Now, children are kept from the

dying process. Death has been moved to the closet where sex used to be. Death has become taboo.[10]

Another change in dying rituals was the wishes expressed by the dying to be considered after burial. Before the 1700s, death was a concern only to the person threatened. Only a legal document for the disposal of property was a concern for family members. [11] After the 1700s, a will became a document that laid out religious services and the legacy the dying wanted to pass on. This document for five centuries was merely a means by which each person could express his thoughts, his faith, and his attachments to possessions and God. Decisions were centered on how to assure the salvation of his soul and the disposition of his body.[12]

B. Philosophical Approaches.

Second, the changing characteristics of dying over time have been accompanied by different philosophical tenets about death. Throughout history, as attitudes and customs towards death and dying changed, two philosophical approaches emerged to guide the dying process, one being physician-centered, the other being patient-centered care.

1. Physician-Centered.

For the philosophical approach that is physician-centered, two interrelated issues are important: the meaning of the Hippocratic tradition and the role of paternalism and beneficence.

Hippocratic Tradition.

The Hippocratic Oath, one of the best-known Greek texts, is one tradition that is still practiced today. With the advent of this oath in 5 BCE, physicians promise to act for

the good and to keep patients from harm. This oath requires physicians to use their skills not as they would prefer but for human benefit. In that pursuit, they are charged to "do no harm." Physicians are also expected to improve their knowledge and skills, increase their competence, and to care about their patients or to be "troubled by another's trouble." The physician has a responsibility to aid and care for a patient even if no cure is available.[13] The Hippocratic tradition is also one of the basic tenants of both Eastern and Western medicine. Physicians *must always* treat a person in need. The Hindu code asserts that all people are to be treated as if they were relatives. The Chinese code emphasizes all are to be treated equally.[14]

Early on during the Hippocratic tradition, medicine was viewed as a "moral enterprise."[15] Physicians were expected to swear to the god's certain loyalties. The Hippocratic Oath also binds the physician to his teacher and the greater community of physicians with specific responsibilities laid out in a code of proper behavior. Part of this code is to demonstrate the beneficial nature of any moral enterprise, the use of medical skills for human benefit. The Hippocratic tradition takes a strong stand against abortion, euthanasia, and suicide. This stance was an opinion of a small segment of Greek philosophy, rather than the prevailing view of most Greeks. Despite this opinion, no disgrace was attached to suicide. Likewise, Greek or Roman law did not protect the unborn child either because these societies, which were pre-Judeo-Christian, did not hold the view that eternal punishment awaited for those who ended their lives or the lives of the unborn.

Paternalism and Beneficence.

Throughout history, the physician lived in a world that made multiple claims on him: demands of his family as well as the state. All expected his loyalty.[16] The church too made claims on the physician; life was to be respected. The church would demand absolute honesty by the physician toward a dying patient who needed to be told everything so that he could prepare himself appropriately and get his house in order.[17] Along with these expectations, paternalism became the norm in the early 20th century. In this philosophy, the physician always knows best.[18] With medical paternalism, a physician ignores the patient's viewpoint and assumes that any disease can be cured. The greatest failure of paternalism is the assumption that medical good is the highest good. An example might be when a physician fails to appreciate the personal values of the patient, which might result in a lengthy treatment regimen that ignores the patient's values. Until modern times, the physician was not looked upon as failing if he were not successful in keeping someone alive. Death was inevitable and thus tolerated by the community and accepted without agonizing fear. Because death hit every age group, it was a routine part of life. People took death calmly, and it had a public character to it. There was no secrecy, no trying to hide it. Death took place amid a circle of family, friends, and children.[19] Because of medical management of death, people now live longer lives but have worse health, experience longer illnesses but slower death, are faced with longer aging and increased dementia.[20] The distorted view, that all diseases are curable and that the sanctity of life can best be maintained through medical science and technology used aggressively against death, is commonplace.[21]

Beginning with the Greeks, paternalism was not as dubious ethically as it is today. The United States culture has grown in the area of individual rights. Medical treatment of old depended heavily upon faith in the physician more so than on therapies or any technology. The social status of a physician, which could lend itself to irresponsible use of power and feelings of superiority, were just some of the problems with paternalism.[22] Paternalism evolved into beneficence. Beneficence means, "do no harm," which resembles passive non-malfeasance. Prevention of harm follows closely. To further move down the order of the beneficence would be to interpret the physician's duty as binding even if it causes discomfort, risk, or pain to the patient. The physician must act in the patient's interest even if it costs to comfort, power, prestige, or fiscal benefit to the physician.[23]

2. Patient-Centered.

For the philosophical approach that is patient-centered, the focus is on patient autonomy and the accompanying conflict that can arise.

Autonomy.

The tidal wave of changes happened in medical ethics starting in 1965, most crucially, the shift from physician to the patient in decision-making. The dignity of the human person is where the model autonomy is grounded. This shift in the locus of control also promoted an unprecedented expansion of medical technology. Similarly, the economic considerations changed as to how physicians viewed their patients.[24] With the expansion of political democracy, the general improvement of education and the increasing moral pluralism in our society have been major forces in the significant growth of autonomy. While paternalism may be appropriate in some situations (such as

treating children or treating patients who are incapable of making autonomous decisions), autonomy is a better option. In emergency rooms, where uncertain prognosis may be the norm, to forgo autonomy, however, may be appropriate at times. These situations would all fall into the "variability context" and require careful assessment in each case.[25]

Conflicts.

In general medicine, medical technologies history is a confluence of three distinctive historical streams: biological research, clinical practice, and the healthcare industry.[26] With the development of the microscope, the germ theory of disease was finally accepted. This led the way for the development of vaccines, public sanitation improvement, and aseptic surgery became a norm. More than any other tool, the microscope may have contributed the most to medical science.[27] With the discovery of x-rays, the ability to see inside the body, which previously had only been a dream, spawned additional tools for mapping and even repairing internal organs.[28] Radioactivity properly harnessed became a powerful diagnostic and therapeutic tool that has led to positron emission tomography scanners, the Gamma Knife, and protein accelerators.[29] Harnessing sound waves were the precursor to the development of stethoscope and the blood pressure monitor. Ultrasound first developed detecting icebergs, and enemy submarines detect flaws in the human body that became clinically useful and an extremely valuable diagnostic tool.[30] With the ability of physicians to repair, replace, and assist failing organs, the need for accurate record keeping and analysis of data became apparent and thus the standard of care. Additionally implanted devices have evolved with the development of integrated circuits and microprocessors and the transition from analog to digital electronics has offered significant benefit.[31] The Internet is now offering

unprecedented access to medical information and treatment options. Health care has embraced the wireless age and telemedicine is now in its infancy with the use of cellular telephone technology that will conceivably change health care forever.[32]

Medical technology has worked wonders although modern medicine is far from perfect. Success often breeds complacency, and potentially an overreliance on medical technology can have a very deleterious impact on the relationship between physician and patient.[33]

Additionally, a conflict has been exacerbated by medical technology, which revolves around the ubiquitous computer.[34] High-tech medicine is now moving to the next level because of enhancement of communications. Physicians have immediate access to medical records, digital scans, x-rays, medical resonance imaging, a whole plethora of needed information.[35] The operating skills of surgeons can be enhanced by video cameras, robotic surgery, and even speech recognition.[36] Some advocates say that the most exciting changes that have happened in healthcare are now the interaction with patients and physicians.[37] Physicians are now being able to expand their portfolio of diagnostic tests and therapies by providing these services to patients in the comfort of their own home. Phone lines or cell signals can be used to monitor, reconfigure, or update medical devices along with medical emergencies that can be reported and responded to immediately.[38]

Unprecedented access to information about medical conditions and treatments are now available through Internet resources.[39] People need access to information to aid in their quest to be good informed consumers of health care and its delivery.[40] Telemedicine has expanded from accessing expert physicians consulting with doctors in rural and

developing areas. The progression of telemedicine medicine now includes radiology services with a remote interpretation of scans and the utilization of robotic tools used by the surgeon. Additionally, telemedicine is now being utilized to more easily communicate and aid the physicians, hospitals, and pharmacies to better manage the patient's medical condition.[41] Smart phone applications have been developed to track patient's medical care, read blood samples and transmit results, remotely monitoring patients in critical care intensive care units, and aiding physicians themselves to be better informed of current technological advances.[42] Ultimately, consumers will be able to effectively monitor their health in consultation with their physician detecting potential problems. Concerns still exist regarding the personal relationship being deleteriously impacted between physician and patient.[43]

II. Medical Futility.

The discussion above on changing attitudes on death and dying offer insight into the ethical debate surrounding medical futility. The discussion over medical futility is fraught with controversy. To discuss medical futility requires examining two related topics: the debate about the meaning of futility and the goals of medicine.

A. Futility Polemic.

First, to clarify the meaning of medical futility, the ethical debate revolves around the definition of futility and the definition of rationing.

1. Defining Futility.

The definition of medical futility can be clarified by considering the purpose of treatment and by looking at an example of a futility policy, specifically the Texas Advance Directives Act.

Purpose of Treatment.

The concept of medical futility is an ancient concept dating back to the time of Hippocrates (d. 375 BCE) when he stated that physicians should not treat those who are overmastered by their disease. Hippocrates realized that in many cases medicine is powerless. Medical futility is a clinical action serving no useful purpose in attaining a goal in the care of a patient. Scholar Griffin Trotter maintains medical futility occurs when: (1) there is a goal, (2) achieving this goal has an action and activity, and (3) achieving that goal will fail with virtual certainty. For the physician to discuss futility with patients and family, three concepts are essential for the discussion. First, treatments that are ineffective or harmful to patients are not obligatory. Second, physicians must engage in dialogue concerning futile treatments. Thirdly, physicians must convey concern even if there is no cure. Providing ongoing care for patients is never futile.[44]

Futility Policy-Texas Advance Directives Act.

On September 1, 1999, the Texas Advance Directives Act became law regulating end-of-life futility. Several provisions are included in this law: addressing the living will, terminal and irreversible illnesses, and witnessing requirements. To take advantage of the law and to create a legal safe haven for institutions and physician, certain provisions must be followed: (1) families must be given written information about hospital policy, (2) families are to be given 48 hours notice and be invited to become involved in ethics consultation process, (3) the family must be provided a written report of the findings of the ethics review process, (4) if the consultation process fails to resolve the issue, the hospital in concert with family will try to arrange transfer of the patient to another physician and institution willing to give treatment that is being refused by the current

team, (5) after 10 days, if no providers can be found, the hospital and physician may withhold or withdraw the treatment determined to be futile, (6) the party who disagrees may appeal and ask a court to grant an extension only if there is a likelihood of finding a willing provider, and (7) if no extension is granted, then the futile treatment can be withdrawn with immunity from civil or criminal prosecution. This is a regulation that mandates the withdrawal of life-sustaining treatment if deemed futile even if it is against patient and family wishes. In theses cases, it needs to be critically reviewed from the perspective of the Catholic Tradition.[45] The Texas Advance Directives Act raises questions from the Catholic perspective of medical futility in light of the observance of the *Ethical and Religious Directives for Catholic Health Care Services*. Directives #57, #58, and #60 address the withholding of medically appropriate treatment, artificial nutrition and hydration, and the prohibition of euthanasia.

> A person may forgo extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the patient's judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community. (Directive #57)

> In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g., the "persistent vegetative state") who can reasonably be expected to live indefinitely if given such care they cannot reasonably be expected to prolong life or when they would be

> "excessively burdensome for the patient or [would] cause significant physical discomfort, instance, as a patient draws close to inevitable death from an underlying progressive and fatal condition, certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort. (Directive #58)

> Euthanasia is an action or omission that of itself or by intention causes death in order to alleviate suffering. Catholic health care institutions may never condone or participate in euthanasia or assisted suicide in any way. Dying patients who request euthanasia should receive loving care, psychological and spiritual support, and appropriate remedies for pain and other symptoms so that they can live with dignity until the time of natural death. (Directive #60)

Tradition teaches that individuals must preserve life, but not by all means. If measures cause a grave burden for oneself or another, then the use of extraordinary efforts should be avoided. Directive #57 morally justifies the patient's decision to refuse treatment, but it does not authorize a patient to request a treatment that is either ordinary or extraordinary. Additionally, Catholic Tradition supports the physician's ability to conscientiously object or to offer treatment. Directive #58 establishes that medically assisted nutrition and hydration is not an absolute necessity if their administration would be harmful to the patient. Therefore, this directive would not be applicable in futile cases.

Directive #60, the forbidding of euthanasia, has to be viewed regarding the intent. Withholding treatment from futile patients is not to end their life. The intent is to remove inappropriate and harmful medical treatments and thus to relieve suffering.[46]

The main concern of the Texas Advance Directives Act from the Catholic perspective is that this law could enable physicians to bypass communicating with families making decisions about end-of-life. Consequently, physicians might go directly to the review committee without any meaningful interaction with family. Granted this could occur, but the data support otherwise. Catholic health care facilities should and often do support use of Texas Advance Directives Act as a model. The law allows the physicians to practice according to their conscience and the law seeks the good of the patient by preventing a prolonged process. The law also tends to improve the quality of end-of-life care in the most difficult circumstances by improving communications between family and staff.[47] Texas is one of only two states with a specific timetable for terminating a patient's life-sustaining treatment. The technology involved in such treatments can be inhumane by causing significant pain and suffering to patients. When patients reach this point, they typically suffer from multiple organ failure and continuation of patient care is imprudent. Additionally, life-sustaining treatment can be very disturbing and distressing to physicians and healthcare providers when witnessing patients' unnecessary suffering.[48]

2. Rationing.

The definition of rationing needs to be separated from futility because they are very different ethical concepts. Defining and the purpose of rationing will be engaged.

Defining Rationing.

Futility at times is confused with rationing, but they are very different ethical concepts. Futility deals with continuing a treatment that has no benefit; rationing deals with withholding a treatment that does have a benefit. This does not mean that rationing is wrong: it can be justified especially from a policy perspective.

Rationing of health care is limiting the availability of beneficial health care. In the United States, few restrictions exist on the use of health care technology regardless of cost or clinical effectiveness. Rationing care by eligibility for insurance coverage is where ethical issues emerge. Health care resources are both explicitly or implicitly rationed and thus limiting access to beneficial health care services. The key question is not whether health care is rationed but how, by whom, and to what degree. Additionally balancing autonomy, beneficence, and distributive justice can create ethical dilemmas. The "rule of rescue" is accomplished in medical care when providing services to the most needy or the most identifiable. Therapeutic services are often given priority over preventive services regardless of goals or cost-effectiveness.[49]

Purpose of Rationing.

The basic purpose of rationing to have a policy that fosters stewardship limited resources and health care. Health care in the United States accounts for the largest percentage of gross domestic product of any other industrialized nation on earth. Only by rationing or setting limits can health care costs be kept from spiraling out of control. These costs are unsustainable for this country as long as there is an increasing demand for expensive technology, fueled by new research discoveries, patient demands for curative therapies, and the tremendous profits that are gleaned from health care. People have

difficulty comprehending the arguments that exist for curtailing health care; arguments are emotionally charged when talking about human pain and suffering. Even though many private insurance companies, Medicare, and Medicaid have placed many restrictions on the ability of doctors to prescribe, operate, and implement, the physician retains significant leverage over what gets offered to the patient. When combining this system with the traditional fee-for-service system, a significant increase in costs occurs.[50] Hence, rationing can be justified from a policy perspective as a function of stewardship of limited resources in health care. This is where rationing and futility achieve similar goals in this sense. Just as rationing from a policy perspective seeks to steward the resources of health care, similarly futility emphasizes the need to withdraw ineffective treatment not only out of respect for the patient but also to steward limited health care resources.[51]

B. Compassionate Goals of Medicine and Health Care.

Second, the debate on medical futility connects the meaning of futility with the goals of medicine. To understand the goals of medicine when facing situations of medical futility, two issues must be addressed: the meaning of compassionate succor and how to deal with end-of-life dilemmas.

1. Compassionate Succor.

The meaning of compassionate succor refers to situations that deal with the prevention of disease and prevention of untimely death. Both will be brought to light.

Prevention of Disease.

Compassion is manifest in the prevention of disease as a goal of medicine. The prevention of disease has three core medical values. First, it is better to avoid disease

when possible. A physician's duty is to help patients stay well. Some contend that the physician who helps the patient remain healthy does them as great a service as caring for them after their disease has occurred. Secondly, there can be a beneficial economic consequence by helping to reduce chronic disease and offering cost-effective health care as well as alleviating dependence on technology. Thirdly, the public at large as well as the medical community needs to be aware that preventive health care has significant benefits and needs additional emphasis.[52]

Society has to begin to develop true compassion. Instead of succumbing to the temptation of self-preservation, humans cannot turn away from the suffering of their fellow man or the suffering children. True compassion must be developed to the point that it promotes the very willingness to help.[53] Ultimately, these facts cannot be ignored: death can only be postponed and the disease itself cannot be overcome. Disease prevention cannot be an absolute priority over other goals of medicine. Illness and death will eventually impact everyone.[54]

Compassion is also indispensable for the alleviation of pain and suffering as a goal of medicine. One of the ancient duties of the physician has always been the relief of pain and suffering. Pain and suffering are not experienced in the same way. Pain often refers to physical distress: throbbing, piercing or burning, whereas suffering usually has a psychological aspect such as fear, dread, or anxiety. Pain, the unrelenting kind, can be a source of suffering but does not always lead to it. Conversely, suffering does not always involve pain.[55] Compassion must always be part of the professional duty of physicians because of their self-image held by the public. Without a doubt, compassion as a duty lies in the connection to other duties (e.g., fiduciary responsibility to the patients, the duty of

due care, and the duty to maintain confidentiality). All of these duties have a powerful relationship to compassion.[56]

The suffering that comes with a disease can be understood and responded to; additionally, it can cause fear, despair, anxiety, futility and even helplessness. These feelings need to be responded to by the physician with compassion. The compassionate physician will put the patient's interest first. Two key elements of compassion include: (1) the capability and eagerness to join deeply enough to gain insight into the experience of an individual suffering; and (2) a virtue personified by the eagerness to ease the person's suffering, or at the very least, to be the medium to help the patient lives through the pain.[57]

In the fiduciary responsibility, a patient's interest is linked to compassion in two ways. First, a physician is best able to interpret where the patient's interests lie. There is important evidence gleaned. A compassionate physician, one who feels the patient's suffering, is best at relieving that suffering. Secondly, alleviation of suffering is usually the patient's main interest. Because compassion means the desire to alleviate suffering, the compassionate physician will facilitate putting the patient's interest first.[58] A compassionate physician also must provide due care. The physician is required to maintain a reasonable range of professional skills and to use them appropriately. Patients have so many varied needs, and there are so many medical specialties having different and evolving standards, the duties of care can vary. The truly compassionate physician will more likely act with due care as circumstances evolve.[59]

In addition to due care, confidentiality is required of the compassionate physician. He encounters a vulnerable patient who may reveal sources of a patient's suffering,

secrets about an undisclosed lifestyle, guilt, emptiness, and even rejection. The compassionate physician will see this duty of confidentiality as a protection of the vulnerable.[60] These duties have a much better chance of fulfillment when a physician brings compassion into the patient encounter. Without compassion, the physician is unlikely to provide the same level of care and much less likely to protect the patient's vulnerability. A transformation has occurred away from the compassionate doctor-patient relationship. This transformation has been a very complex process.[61]

Medicine has been profoundly affected by the embracing of science. Science uses methods that are value free. First, a hierarchy of values in medicine has existed: the patient is first, the doctor must do no harm, and the patient's good is paramount. Science deals in generalities, not specifics.[62] Secondly, technology has impacted the character of the physician. Science and technology have mistakenly been construed to be the same about the thinking and behavior of the physician. Thirdly, a new model of a physician has emerged that is academically minded and differs from the physician's role of the past. There has been a general mistrust of science resulting in a redefinition of patient-hood. The patient has become so knowledgeable that the physician can no longer advance the idea that he is the sole owner of medical knowledge.[63]

The outcome of this new model could be an avoidance of pain and suffering in the patient. Pushing acknowledgment out of the physician's conscious awareness has occurred when emotional expression by the patient has been distressing, disconsolate, fearful or even despairing. When the physician's presence is called for, he still may avoid direct contact by employing excuses. Avoiding unpleasantness can be described as normal; but actually, it may suggest the physician's emotional issues.[64] Helplessness and

role inadequacy are other reasons that a physician may avoid pain and suffering. Studies have suggested that the health of the physician may be compromised if he does not acknowledge his own emotions. As a result, the quality of medical care can be compromised. When patients feel abandoned or rejected by the physician, the call "to do no harm" and to benefit patients can be ignored. When patients are avoided, the physician misses opportunities to appreciate the patient's experience and may not adequately address symptoms.[65]

Prevention of Untimely Death.

Another goal of medicine is the prevention of premature death for which compassion is central. Many challenges are going to be encountered if medicine chooses to move toward compassion. The essential challenges are that of mindfulness and self-awareness of the physician. Tremendous opportunities exist for medical education to establish a foundation for the physician's well-being and quality care of the patient.[66] An important goal of medicine has always been the struggle against death. Medicine's duty to accept death as the destiny of all humans must remain in healthy tension. In medicine today, its first aim should be to reduce premature death. The secondary purpose is proper care for those whose death is not premature. These people too can benefit from medical treatment.[67] A premature death is one that occurs without a person having an opportunity to experience a complete human lifecycle. Death may be premature if it could have been prolonged without great torment to the individual or society. The extension of life for its sake should not be an appropriate medical goal.[68]

Finally, compassion is indispensable in attaining a central goal of medicine: the support for a peaceful death. A peaceful death is one with diminished pain and suffering

yet the patient never feels like he has not been abandoned nor has not received an appropriate end of life care. A death such as this can never be guaranteed by medicine, but medicine can avoid treating death as medical failure. To help facilitate a peaceful death, a physician must act compassionately at every opportunity.[69] A peaceful death should be provided by medical treatment that is appropriate. Today in medicine, death is often treated as the supreme enemy. In its effort to banish death, however, medicine has come to believe it has the power to change, to control, and to eradicate a disease. Medicine has dissolved the line between human power and nature's power. Initially, death was understood as a natural event, something that happens to everyone and everything. Death had been experienced as evil; not a moral evil, but an evil of religion or something in the abstract. As medicine's effectiveness changed, the view of death has taken on a moral dimension and fatalism has been eliminated. But with this moral view comes a moral obligation to use every means possible to ward off death.[70]

Under the moral view, if the patient dies the physician has failed. The more control over death that medicine has exercised, the more the demand on morality has increased. The metamorphosis of death from a biological evil to a moral evil has occurred. The tension has now been created between what one can do medically and what one ought to do morally. The emphasis has been placed on medical advocacy rather than what is morally correct.[71] In this transformation of death, one of the by-products that have been lost is compassion. The behavior of a kind and caring physician is desirable because that attitude not only reveals consideration for the patient, but also an authentic attitude of compassion that fosters trust in the patient which is rarely found. The caring and compassionate physician who manifests the recognition of suffering and the desire to

help is often missing. Compassion does not cost extra time or resources but offers confidence that can improve the patient's well-being.[72]

As medical technology advances, the line between living and dying is hard to determine. Medicine has changed the focus from death being a biological fact to focusing on the single-mindedness of the causes of death. Society and medicine have come to accept that human agency has replaced the power of nature. A fusion of technology and the sanctity of life have created tremendous pressure against the acknowledgment of death.[73] An overwhelming temptation exists to take control over life and death; this is a result of technology. More options in health care do not mean better health care. Compassion comprehends the dignity of the sick and honors that patients are full participants in their healing, partnering patients and physicians, especially at the end of life when technology gives all tremendous power. Often technology substitutes for compassionate care. Compassion can be defined as neither under treatment nor overtreatment.[74]

The Human Genome Sciences Chief Executive Officer, William Haseltine (b. 1944) articulates the epitome of the attitude of death avoidance: "Death is nothing but a series of preventable diseases." Cures would be the result of finding the genetic source of disease. This, in fact, has not proved to be the case. Nevertheless there is an optimistic push to continue in that vein. Countering that way of thinking is the palliative movement, trying to bring the "tame death" back into reality.[75] "Tame death" is the concept coined by the French scientist Phillipe Aries (d. 1984) referencing the acceptance of death as part of nature.[76]

Technologies have extended dying but have not cured diseases as promised. The use of technology has been driven by overpowering incentives that include fee-for-service medicine, excessive medical training in the use of technology, the fear of litigation, patient demands, and consumer advertising. All of these incentives cause physicians to be even less compassionate.[77] Medical technology is one of the greatest enemies of a good death. The myth of the utopian concept against mortality has spilled over into the culture expecting medical miracles. The public has been duped, expecting that life should not end.[78] Physicians who have been taught to push patients not to give up have exacerbated hope in technology. A moral obligation "to push on" regardless of the potential for positive outcomes has become an accepted norm.[79]

An illustration of this phenomenon: An elderly female patient with multiple comorbidities on ventilator support as well as extensive medical interventions was unconscious and deemed unable to make her own decisions. She did have medical power of attorney but no advance directives. After a significant conversation with the niece, the surrogate decided to withdraw life-sustaining therapies. She advised the critical care physician of her intent to withdraw. The physician went to the unconscious patient and shook her and said: "You don't want to die, do you? You can't give up!" Not only was this behavior unprofessional, but also revealed his lack of compassion. Although this was blatantly unprofessional, it has been observed that often the exact opposite situation occurs. The patient or his surrogate demands all treatment possible regardless of its benefit, even to the point of medical futility. In those cases, the compassionate physician faces a significant dilemma.

Society and the physicians exhibit compassion in different ways while pursuing the goals of medicine. Preventing disease and suffering while fostering a peaceful death are explained. Compassion must be given a greater prominence in society and health care. A greater concern for one's fellow man is paramount. Society needs to change so the patient and physician can have compassionate, healthy discussions without the pressure from society to do everything and where doing nothing does not seem morally wrong. Humans must realize their obligation to take better care of themselves and take responsibility for their health care.

To this end, health care is now moving more into the community with less emphasis on bricks and mortar. The idea of preventive health is being promulgated by the health care industry. With the advancement of technology, there are virtual emergency departments with real-time diagnosis, cause, treatment, and prognosis all being done in the patient's home. The goal is to improve the community's health and to alleviate the need for hospitalization. Ultimately, these changes will have a significant impact on distributive justice, limited resources, and the common good of all. Additionally, compassion needs to be reinserted into the physician's capacity to serve his fellow man. Medical schools and medical training must be reinvigorated with compassion for the patient. In this systematic change in the delivery of health care, compassion needs to be recognized not only as an additional benefit but also as a crucial duty of all physicians.

2. End-of-Life Dilemmas.

The end-of-life dilemmas raise ethical issues about balancing criteria of burden versus benefit and about the sanctity of life. Both will be discussed.

Balancing Criteria.

Modern medicine has postponed the natural course of dying. Patients are now subjected to prolonged lives and acute complications thus forced to make decisions about how vigorously to treat and when it is morally permissible to withhold or withdraw life-sustaining measures. The most judicious in helping to resolve these moral difficulties is to develop a combination of subjective and objective criteria. Striking a balance between three criteria: effectiveness, benefit, and the burden are the moral calculation being used. Effectiveness estimates the capacity to alter the disease or symptom positively. Benefit refers to what is valuable to the patient centering on the patient's assessment of his own goals. Burden refers to the physical, emotional, fiscal, or social cost imposed on the patient. If the assessment of these criteria is favorable to the treatment then it is morally justifiable; when it is unfavorable, then it is not morally justifiable. Clinically these criteria give some clarification to what is ordinary and what is extraordinary.[80] Finally, a fundamental distinction needs to be highlighted between ordinary and extraordinary means in the *Ethical and Religious Directives for Catholic Health Care Services*. The distinction refers to the use of the prepositions "and" highlighted in the *Ethical and Religious Directives for Catholic Health Care Services* quotation above. Patients must use means that are ordinary. This means when there is both a benefit and no excessive burden or expense. In contrast, patients have no obligation to use means that are extraordinary (this means when there is either no benefit or an excessive burden or expense). In other words, there is a much lower ethical bar to establish treatments as being extraordinary and hence morally optional.

Sanctity of Life.

A major moral tradition in healthcare is the sanctity of life. The term has a relatively modern usage. The concept of the preservation of life is as old as life itself. When used in a restrictive sense, it connotes the dominion of God. In a universal sense, it emphasizes stewardship to help determine obligations faced regarding health care and other quandaries. When the sanctity of life is used as stewardship, then stewardship becomes a task rather than a boundary line.[81] Respect for life and sanctity of life can be used interchangeably. In the biological sense, both respect the existence of a living human organism for human individuality and the personhood.[82]

Historically, there seems to be a reverence for life, making the deliberate killing of another person a punishable offense. Aversion to murder in all societies is the most universal of all moral attitudes. Abortion, euthanasia, and suicide have not shared that commonality. In Greek and Roman society, there was some disapproval of abortions and even some legal prohibition.[83] Some Greek philosophers even looked at abortion, as a way to control population and it was essential for a well-ordered community. The Judeo-Christian tradition significantly impacted the evolution of the belief that abortion and suicide were morally wrong. Most people in the West regard life as something sacred and hold that no one can dispose of it whether by murder, abortion, or suicide. The reason that killing is forbidden is based on Divine prerogative and divine rights.[84]

The term "sanctity of life" has become an all-encompassing term to include all life regardless of quality, even to prolong dying. Invoking the term "sanctity of life" may be going too far when it is used in the argument against abortion. The term can be an all-

inclusive term with no limitations. The use of this term can be problematic because there are times when an abortion may be morally allowed.[85]

When the universality of the term "sanctity of life" is used it gains a very positive orientation rather than emphasizing the things one cannot do. At that point, the sanctity of life can help guard against the erosion of the respect for life; even in protecting gravely ill patients who are vulnerable.[86] Sustaining life reflects the doctrine of the sanctity of life. But to what limits are we to prolong life? Roman Catholic ethics prohibits the termination of life intentionally, but it does permit withdrawing futile treatments to let patients die. Given that life can be prolonged by medical intervention there is a temptation to consider that it should be continued at all cost. However, the Catholic Traditions doctrine on the sanctity of life is so robust as to respect life by withdrawing futile life-sustaining treatment. Naturally, there are both philosophical and practical uncertainties about went to withdraw futile treatment to let a patient die. The traditional doctrine about the sanctity of life is consistent with the view that there is an important distinction between ordinary and extraordinary means of preserving life.[87]

III. Withdrawal of Life-Sustaining Treatment.

Related to the above discussion regarding attitudes to death and medical futility, is the ethical debate around the withdrawal of life-sustaining treatment. This discussion requires consideration of two related topics: artificial nutrition and hydration and the relief of suffering at the end-of-life.

A. Medically Assisted Nutrition and Hydration.

First, assisted nutrition and hydration is especially significant as a medical intervention at end-of-life and for patients in a persistent vegetative state.

1. Role at End-of-Life.

In this section, the end-of-life ethical debate on medically assisted nutrition and hydration revolve around clarifying its medical purpose and how these encounter cultural pressures.

Medical Purpose.

Two main reasons are cited for using technology to initiate assisted nutrition: to improve fatigue and to avoid "starving to death." Sometimes clinicians and families believe the reason the patient is weak is that they are not eating. No evidence exists that supports assisted nutrition improves energy level or survival except patients who are for mechanical reasons not able to eat. The data suggest that an increased risk of aspiration and other complications-infection, obstruction, edema, and pneumonia are more likely to occur when patients are supported with assisted nutrition. Often the conversation around nutrition and hydration has to do with the patient and family's acceptance of dying than it does about intervention. Assisted nutrition and hydration is now a medical therapy rather than providing sustenance. All stakeholders (physicians, patients, and caregivers) need to understand what the likely outcome is in each situation. In prolonging life, medically assisted nutrition and hydration can be invaluable. At the end of one's life, its usefulness comes into question. The decision to administer medically assisted nutrition and hydration has to be individualized in light of the goals of care of the patient.[88]

Cultural Pressures.

Family members often feel helpless in the face of disease progression. Their common concern is, "Will our loved one endure more pain and suffering without food and fluids?" Studies have shown that feelings of hunger are absent from patients who are

nearing end-of-life. Thirst can be a major discomfort, but there seems to be no correlation between the intake of actual fluid and the sensation of thirst. Dehydration may have benefits at the end-of-life by aiding in the release of endorphins that offer natural pain control as the body shuts down. Releasing endorphins can also aid in the improved quality of life due to the elevation the patient's mood. If fluids are increased, there may be increased urinary output and thus the need for a urinary catheter. Food and fluids also increase gastrointestinal activity potentially causing the patient discomfort due to abdominal distention, nausea, vomiting, and diarrhea. With the addition of fluids, an increase of oral and airway secretions will develop allowing for potential aspiration pneumonia, coughing, congestion, and or difficulty in breathing.[89] Two main reasons are cited for using technology to initiate artificial nutrition: to improve fatigue and to avoid "starving to death." Sometimes clinicians and families believe the reason the patient is weak is that they are not eating. No evidence exists that supports medically assisted nutrition and hydration improving energy level or survival except patients who for mechanical reasons are not able to eat. The data suggest that an increased risk of aspiration and other complications (infection, obstruction, edema, and pneumonia) are likely to occur.[90] Often the conversation around nutrition and hydration has more to do with the patient and families' acceptance of dying than it does about intervention.[91] Assisted nutrition and hydration is now a medical therapy rather than providing sustenance. All stakeholders (physicians, patients, and caregivers) need to understand what the outcome is in each situation. In prolonging life for some, medically assisted nutrition and hydration can be invaluable; but to relieve pain and to suffer at life's end, its

usefulness comes into question.[92] The decision to administer medically assisted nutrition and hydration has to be individualized in light of the goals of care of the patient.[93]

The Catholic Church addresses medically assisted nutrition and hydration in Directive #58 of the *Ethical and Religious Directives for Catholic Health Care Services*. "Certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort."[94] The issue of medically assisted artificial nutrition and hydration, however, is being co-opted by the right-to-life and sanctity-of-life arguments with no consideration of the data that supports withholding medically assisted artificial nutrition hydration. The medical data is not given credence. Potential pain and suffering and the prolongation of death that are not ordinary.

2. Persistent Vegetative State Patients.

Medically assisted nutrition and hydration is used for patients in a persistent vegetative state. The ethical debate here needs to have a clear definition and moral direction.

Definition.

The persistent vegetative state is a clinical condition of complete unawareness of self and the environment, accompanied by sleep-wake cycles, with either complete or partial preservation of the brain and brainstem function. Patients in a persistent vegetative state show no evidence of sustained, reproducible, purposeful, voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli. Persistent vegetative state patients show no evidence of language comprehension or expression, have bowel and bladder incontinence, and have variably preserved cranial nerve and spinal reflexes. A

vegetative state is present one month after acute traumatic or non-traumatic brain injury or lasting for at least one month in patients with degenerative or metabolic disorders or developmental malformations. The recovery of consciousness is unlikely after 12 months period.[95]

Moral Direction.

In the papal allocution March 20, 2004, the Pope John Paul II (d. 2005) stated that hydration and nutrition are a morally ordinary treatment for persistent vegetative state patients and that foregoing would be considered "euthanasia by omission." Even though this allocution has been judged by some theologians not to be consistent with the balance of Catholic teaching on forgoing treatment, it was a papal address given much attention and thus has led to significant debate about persistent vegetative state patients. One of the impacts of the allocution has been the rewriting Directive #58**.**

> In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g., the "persistent vegetative state") who can reasonably be expected to live indefinitely if given such care they cannot reasonably be expected to prolong life or when they would be "excessively burdensome for the patient or [would] cause significant physical discomfort, instance, as a patient draws close to inevitable death from an underlying progressive and fatal condition, certain measures to provide nutrition and hydration may become excessively burdensome and

therefore not obligatory in light of their very limited ability to prolong life or provide comfort. (Directive #58)[96]

An extensive survey of relevant medical literature dealing with this issue and different positions taken by moral theologians has been conducted. In the review of the theological opinions, there was not found persuasive rationale by some theologians that since persons in persistent vegetative state conditions can no longer pursue the spiritual goal of life, feeding them artificially would be considered futile. Medically, life expectancy usually ranges from only two to five years thus arguing persistent vegetative state patients are in a terminal condition.[97] The *Ethical and Religious Directives for Catholic Health Care Services* implement the teaching of the Papal Allocution: "in principle, there is an obligation to provide patients with food and water, including medically assisted hydration and nutrition" even for patients in the "persistent vegetative state." However, there is a crucial qualification of this "in principle" doctrine when applied to specific cases in which the "obligation" becomes "morally optional." The Bishops explain: "medically assisted hydration and nutrition become morally optional when they cannot reasonably be expected to prolong life or when they would be excessively burdensome for the patient." The Bishops further clarify, "certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory." [98]

B. Relief of Suffering.

Second, the withdrawal of life-sustaining treatment is designed to address the relief of suffering at the end of life. This raises specific ethical concerns regarding palliative care and assisted suicide.

1. Palliative Care.

In addressing palliative care, two interrelated concepts need consideration, care at end-of-life and palliative sedation.

Care at End-of-Life.

The fear of killing patients by excessive use of medications, particularly opioids, spurred the debate about palliative care. It received its initial place as a viable service to health care from the time when the pain was often badly managed, and health care professionals were poorly trained. Palliative care has broadened its scope of service to include all acute patients, not just end-of-life. In caring for the dying, it has been determined that there was a need to address both pain and suffering to accomplish a good death. Not all patients come to acceptance of a good death, thus a source of suffering. Careful management of this group of dying patients is what palliative care is called to do. Both doctors and families sometimes find it difficult to accept that a patient is dying, because of the difficulty of determining a clear line between living and dying. Person-centered, family-oriented, and evidence-based care at the end-of-life is the ultimate goal of palliative care.[99] Palliative care provides relief from pain and other symptoms and supports quality of life while focusing on the patient and families. Palliative care should be introduced early in the course of an illness and can be provided throughout the continuum of care whether in home, hospital, nursing home or assisted living facilities. Palliative care is care provided by an interdisciplinary team. These palliative care teams include physicians, specialty advanced practice nurses, registered nurses, social workers, and chaplains.[100]

To enhance palliative care's progress, two important deficiencies exist that need addressing. First, clinicians caring for the patients have deficiencies in their knowledge of caring for people with serious illnesses and nearing end-of-life. Secondly, shortages of palliative care specialist exist, and thus the caring for end-of-life patients often falls to the primary care physicians who have limited skills in this specialized area of health care. Palliative care training and education need to be implemented in medical and nursing schools and encouraged in undergraduate and graduate programs, as well as emphasized in continuing education.[101]

Patients near the end-of-life often have multiple transitions; these transitions can cause medication errors, poor care planning, lack of coordination of care, and the expertise and continuity of care become even more critical. Often patients are so confused and overwhelmed that they struggle with meeting basic needs. Thus, the follow-up care and medication lapses are not outside the norm. Programs to reduce readmission rates and improve primary care have been initiated. Palliative care programs, often in clinics or homes, provide an umbrella that encompasses a spectrum of approaches for bringing care to people with serious illnesses.[102]

Quality of life improvement for both patient and family is a palliative goal. Palliative care provides pain control as well as providing relief from other distressing symptoms; and in doing so, intends to neither prolong life nor hasten death. Palliative integrates psychosocial and spiritual aspects and offers a support system for families and patients with one of its goals being that patients can live as actively as possible until death. Palliative care uses a team approach to address the needs of patients and families.[103]

Twelve key core components have been proposed for the care the patients at the end-of-life. These core components require flexibility and individual tailoring. Management of pain and emotional distress, counseling, family support, frequent assessment, access to coordinated care are just some of the major components that can bring better care to the patient that is nearing death.[104] Palliative care affirms life by supporting the patient and their families' goals including their hopes for life prolongation, as well as their hopes for peace and dignity throughout the disease process, the dying process, and to death.[105]

Performing the skills and applying the knowledge of palliative care initially can be learned and replicated. What is more important is the need to go deeper into the culture of Catholic health care ministry. The Catholic Church has been relatively quiet and lacks leadership in palliative care although the Pope recently spoke out about its value and needed for expansion. In his speech to the Pontifical Academy for Life, he shared the view that "palliative care expresses the typically human attitude of caring for each other especially for those who are suffering."[106]

The Church has taken a more active role in advocating for palliative care because it exemplifies the best of what the Catholic faith has consistently believed and emphasized about one's relationship to God and each other and the meaning and purpose of one's existence. When one reaches out to heal and care for the sick, the poor, the vulnerable, and the dying, one touches God. Fundamental features of the gospel distinguish Catholic health care: (1) Jesus' healing ministry is incarnational. When one cares for others, one is reaching out to Christ himself, (2) Jesus' healing ministry is the work of evangelization. The healing ministry of Jesus brings about the "Reign of God"

restoring people to their communities, (3) Jesus' healing ministry is the work of compassion. Compassion means, "to suffer with" but it is much more than that: it goes beyond sympathy or pity. Compassion is a call to action: to serve the marginalized, the most vulnerable, the forgotten or abandoned, or those suffering. Compassion is an antidote to despair felt by people who believe they have no control or have been abandoned or left to languish, (4) Jesus' healing ministry is the work of restoration of a person to the relationship with God, to their families, to their loved ones, and to their communities. When one offers comfort even when there is no cure, one is ultimately restoring people to their community. Therefore, palliative care is a genuine hallmark of Catholic health care.[107]

Palliative Sedation.

Symptom control (pain, dyspnea or shortness of breath, restlessness, and nausea/vomiting) is one of the cardinal reasons for a good death not being achieved. When symptoms are not controlled, patients often request an alternative means of dying. Physicians often hesitate to give dying patients adequate symptom control for fear that high doses of medication can suppress breathing and cause death. Inadequate training of physicians in symptom control has led to this fear. Causing death by overmedicating is based on false assumptions. Even oncologists, who deal with patients' most in need of symptom control, have insufficient knowledge in the appropriate medical use of analgesic drugs. Large doses of morphine may well cause death if given to a healthy person who is not in pain and has not received morphine before the administration. If administered for pain, the patients' pain receptors will take up such drugs first. Patients whom regularly receive morphine for pain quickly build up resistance to the side effects. Because of this

resistance, patients can tolerate higher doses that would normally be fatal to a healthy person. Additionally, tolerance is built up to the side effects far more quickly than to the analgesic effects. Physicians, therefore, should not hesitate to increase dosages to accomplish pain relief. The dosage needed to relieve pain for patients who are awake and in pain is one that is adequate to relieve the pain. That dosage can be administered without reservation. The risk of increasing the dose to a point where it would cause death is virtually zero.[108]

Palliative sedation has been approved and endorsed by the American Medical Association, the American Nurses Association, the American Academy of Pain Medicine, and the American Academy of Hospice and Palliative Medicine.[109] These organizations agree that rarely is it necessary to sedate patients to the point of sleep to accomplish symptom control. Sedation for the control of intractable suffering in an imminently dying patient is humane, appropriate, and medically acceptable. Patients will not die from the sedation; but it can make the suffering bearable, allowing time for medical teams to reassess patients' further needs. Sedatives can be withdrawn, and patients will be brought back to consciousness to assess symptom control. If symptoms are not controlled, patients can be returned to a sleep state where alternative modalities can be utilized.[110] Palliative Sedation Therapy is the use of specific sedative medications to relieve intractable suffering from refractory symptoms. Refractory symptoms are symptoms that physicians determine cannot safely be relieved by other interventions. Such symptoms requiring sedation include (in descending order of frequency) delirium (55%-65%), dyspnea (26%-27%), pain (14%-18%), and vomiting (4%).[111] The relief of refractory pain can be accomplished by the reduction in patients' consciousness. The

medications used include benzodiazepines, phenobarbital, or propofol. Opioids such as morphine should not be used for Palliative Sedation Therapy because even in high doses, sedation may not be accomplished. Relief of refractory symptoms is the goal. Therefore, care must be taken in choosing doses of sedatives to reduce patients' level of consciousness. Sedation can vary, but initially, the doses should allow for patients' ability to communicate.[112]

Palliative sedation should not be entered into without serious consideration. Ample conversations with the physician, the interdisciplinary team, the patient, and the family need to occur before beginning palliative sedation. These conversations can aid in helping to assuage the concern and answering the questions of right time, right circumstances, and correct intentions.[113] Families often are dubious initially about Palliative Sedation Therapy. Research has revealed that families overwhelmingly (88%) agree that palliative sedation helped to decrease symptom distress. Families disagree, however, that palliative sedation was not dignified and that no meaning was found in being with sedated patients. The families in the research believe that palliative sedation is beneficial, yet they needed to be reassured that no alternative solutions were available. Families need clear explanations and ample time to say good-bye.[114]

Varying degrees of unconsciousness in dying patients can occur with palliative sedation. Due to the concerns about sedation and the inadvertent hastening of death, there may be a need to establish ethical justification using the principle of double effect.[115] The principle of double effect helps to answer the question: Can it be right to have an action that may have two or more effects: some which are good, the intended; and some that are bad, but not intended? The principle of double effect is justified when all the following

conditions are met: (1) the action cannot be morally wrong, (2) the bad effect must not cause the good, (3) the intention must not be for the bad effect, and (4) the bad must not outweigh the good.[116]

In evaluating the sedation of patients with intractable symptoms at the end-of-life is by definition a good action and could be considered a moral obligation by the principle of double effect conditions. To the second condition, the distinction between means and the effects, patients do not have to suffer until the end-of-life. The third criterion regarding intent is to relieve patients' intractable symptoms rather than to hasten death. The final condition questions proportionality. Symptom relief at the end of life does justify the action of palliative sedation. Studies have shown that once intractable symptoms are relieved, patients may live longer. Furthermore, many health care professionals agree that palliative sedation is ethically justifiable. Providing relief, not hastening death, by targeting symptoms while minimizing the potential harm is the goal.[117]

2. Assisted Suicide.

Assisted suicide raises issues related to symptom control and patient autonomy. These, in turn, will be engaged.

Symptom Control.

Physician-assisted suicide can be of real interest to people as they near death because of their fears of an inability of medical technology to control symptoms. The predominant reason for requesting physician-assisted suicide is symptom control. The most common argument in favor of physician-assisted suicide is that death offers the only means of attaining comfort or dignity for the patient in extreme duress. Advocates for

Physician-assisted suicide supplement their argument with data showing that inadequate symptom control is the main reason to request physician-assisted suicide. With physician assistance, expertise is provided to increase the likelihood of a successful suicide attempt. It is argued that with a physician-assisted suicide; such assistance prevents a greater harm than it causes. Advocates for physician-assisted suicide also argue that the immediate death is preferable to suffering from pain.[118]

Paradoxes have surfaced in the argument about physician-assisted suicide. The first paradox is the result of the polemic relationship between autonomy and the principle of beneficence, the relief of suffering. Both autonomy and beneficence are the two major justifications for euthanasia. Physician-assisted suicide ultimately gives individual patients control over their dying, but the result is an increase in the medical power. The second paradox, one of the stated goals of physician-assisted suicide's advocates is to bring about a good death. The good death has been threatened because of the lack of range of options to accomplish it.[119]

One of the important tenants in the debate on physician-assisted suicide is the respect the principle of autonomy. Determining one's life direction is the foundation for autonomy. If in seeking assistance in dying from a physician, then it can be brought into question whether autonomy of the patient is truly respected. In spite of many theories about autonomy, there is agreement on three conditions. The first condition is independence from influences that would be considered controlling. The second is the capacity for action; and finally, the comprehension of the information given. If physician-assisted suicide is requested from patients in extreme suffering, their autonomy is constrained because there is no independence. Respecting patient autonomy does not

involve doing everything patient request. A positive obligation to grant the patients' request only can be granted if there is enhancement or restoration of autonomy. Killing the patient would not restore autonomy; in fact, it would eliminate it.[120]

Beneficence can play a key role in discussions about physician-assisted suicide. In the traditional argument for mercy, no one should have to endure terminal suffering. If the patients' symptoms cannot be controlled because technology cannot offer relief, then the argument goes that the physician should be allowed to bring about death.[121] Utilizing palliative sedation, this argument has less validity. Additionally, when considering beneficence, a capacity to recognize the relief of suffering is required. With physician-assisted suicide, the end of suffering is brought about by the elimination of the suffering patient who no longer can notice the diminished suffering.[122] Proper symptom control does reduce the need for helping patients kill themselves.[123]

The Church is clear about its stand on physician-assisted suicide /euthanasia. "Euthanasia is an action or omission that of itself or by intention causes death to alleviate suffering. Catholic health care institutions may never condone or participate in euthanasia or assisted suicide in any way. Dying patients who request euthanasia should receive loving care, psychological and spiritual support, and appropriate remedies for pain and other symptoms so they can live with dignity until the time of their natural death."[124]

Autonomy.

Loss of autonomy and a diminished quality of life are also offered to justify Physician-assisted suicide. One of the most important tenants in the debate on physician-assisted suicide is the respect for the principal of autonomy. Determining one's life direction is the foundation for autonomy. In seeking assistance in dying from a physician,

it can be brought into question whether autonomy of the patient is truly respected. In spite of many theories about autonomy, there is agreement on three conditions. The first condition is independence from influences that would be considered controlling. The second is the capacity for action; and finally, the comprehension of the information given. If physician-assisted suicide is requested from patients in extreme suffering, autonomy is constrained because there is no independence. Respecting patient autonomy does not involve doing everything the patient requests.[125]

This chapter has extended the discussion of medical technology from the start of life to address end of life dilemmas. The contribution of the Catholic Tradition is to be highly attuned to protecting the dignity of the patients, especially at the end of life and even when they request medical technology for assisted suicide. The Catholic Tradition urges the use of medical technology to alleviate patient suffering without intending their death.

IV. Critique Based on the Ethical and Religious Directives.

As mentioned in Chapters 3, 4, and 5, the Catholic Tradition's use of Natural Law has two general approaches. The first approach focuses on the universal aspect of human nature. This approach is typically associated with the settled Catholic teaching on morality. The second approach focuses on the person, presenting a dynamic and historical view of the human condition as contributors to God's creation.[126] This approach is typically associated with the Principle of Double Effect to apply traditional Church teaching in a flexible manner to changing circumstances. Arising from these two approaches to Natural Law, a third approach has emerged combining the nature-oriented

and person-oriented approaches to new dilemmas regarding emerging technologies that may require doctrinal development in Catholic teaching.

In the conclusion of each applied chapter, a critique based on the Ethical and Religious Directives is presented regarding the main topics of the chapter. The critique adopts the above approaches to identify three distinct categories as follows. Category A deals with settled issues in Church Teaching reflecting the Nature Approach to Natural Law. Category B deals with the controversial issues eligible for using the Principle of Double Effect reflecting the Personal Approach to Natural Law. Category C deals with issues requiring doctrinal development in Catholic teaching to address new dilemmas regarding emerging technologies.

The following analysis applies this threefold critique to the topics discussed in this chapter on death and dying technology. Each main section is discussed in turn.

Section I: Changing Attitudes towards Death and Dying.

This section discussed how even with changing attitudes towards death and dying, the Catholic Church has settled teaching on two pivotal points on this issue: first is the legitimacy of interventions to prolong life; secondly, life is not absolute hence there is no obligation to prolong it at any cost. These points are settled Catholic teaching (Category A).

The *Ethical and Religious Directives for Catholic Health Care Services* give us the moral guidance regarding care for the seriously ill and dying. Directive #56 and #57 address these concerns.

> A person has a moral obligation to use ordinary or proportionate means of preserving his or her life. Proportionate means are those that in the

> judgment of the patient offer a reasonable hope of benefit and do not entail an excessive burden or impose excessive expense on the family or the community. (Directive #56)
>
> A person may forgo extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the patient's judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community. (Directive #57)

Recognizing that ordinary and extraordinary treatments are moral distinctions and not medical distinctions are most critical. The life we have present is a treasure but extending that life by extraordinary means is not obligatory in Catholic teaching.[127] We are not the masters of our lives, we are custodians of it. Ultimately we are to be in union with God, thus if the patient deems treatment excessively burdensome then prolonging life is not mandatory. We are not to desire a long life but a good life.[128]

Section II: Medical Futility.

The next section discussed the ethical issues around medical futility. There is no obligation to continue futile treatment- that is settled Catholic teaching (Category A).

Futility is appropriately addressed in Directive #56 and #57. Treatment after the determination of medical futility is contrary to standards of care and a compromise of human dignity. Often, continued treatment in these cases is a result of the technological imperative.[129]

It is important to distinguish the withdrawal of futile treatment from rationing. Rationing deals with refusing treatments (due to scarce resources) that have a beneficial effect. In contrast, futility deals with providing a treatment that has no beneficial effect.[130]

Another topic in this section deals with the compassionate goals of medicine and health care. Naturally, seeking these goals as a moral obligation is settled Catholic teaching (Category A).

People often think of compassion as an individual virtue or practice, done by one person to help another. Compassionate goals, sympathy with or feeling for the plights of a particular person is what should motivate our actions. Personal compassion is a key element the Catholic teaching to bring healing and relief to people. Also, compassion has a critical medical dimension: the prevention of disease and the alleviation of pain and suffering. Compassion must always be part of the professional duty of physicians. Compassion as a duty lies in the connection to other duties (e.g., fiduciary responsibility to the patients, the duty of due care, and the duty to maintain confidentiality).[131]

Section III: Withdrawal of Life-Sustaining Treatment.

The next section discussed the withdrawal of medically assisted nutrition and hydration when circumstances justify doing so. Justification for doing so is based on there being no moral obligation to use extraordinary treatment, as discussed above. This is settled Catholic teaching (Category A).

However, removing life-support from patients in a persistent vegetative state can be controversial but can be justified as "morally optional." The Ethical and Religious

Directives explain how this is justifiable, adopting the Principle of Double Effect (Category B).

> In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g., the "persistent vegetative state") who can reasonably be expected to live indefinitely if given such care they cannot reasonably be expected to prolong life or when they would be "excessively burdensome for the patient or [would] cause significant physical discomfort, instance, as a patient draws close to inevitable death from an underlying progressive and fatal condition, certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort. (Directive #58)

As a result of the case of Terri Schiavo, Pope John Paul II published a Papal Allocution in 2004.[132] The focus was on the question of medically assisted nutrition and hydration, which is especially complex for patients who have cognitive impairments.[133] The Papal Allocution led to the revision of the Ethical and Religious Directives. That revision included Directive #58 that accepts the justification of withdrawing life-sustaining treatment from patients in the persistent vegetative state (that is, such treatment can become morally optional).

Furthermore, there is continuing data that utilization of medically assisted nutrition and hydration for many patients may not be as beneficial as anticipated.[134] For example, the American Geriatrics Society has explained in its statement on Feeding Tubes in Advanced Dementia:

> 1. Percutaneous feeding tubes are not recommended for older adults with advanced dementia. Careful hand feeding should be offered; for persons with advanced dementia, hand feeding is at least as good as tube feeding for the outcomes of death, aspiration pneumonia, functional status and patient comfort. Tube feeding is associated with agitation, increased use of physical and chemical restraints, and worsening pressure ulcers.
>
> 2. Efforts to enhance oral feeding by altering the environment and creating patient-centered approaches to feeding should be part of usual care for older adults with advanced dementia.[135]

Another topic in this section on withdrawing life-sustaining treatment deals with palliative sedation. Two points can be made with regard to Catholic teaching.

First, in exceptional cases, while controversial, palliative sedation can be justified using the Principle of Double Effect in Catholic teaching (Category B). In other words, the use of palliative sedation can be justified using the Principle of Double Effect.[136] Second, the routine use of palliative sedation for terminally ill patients whose pain may otherwise be manageable would require doctrinal development in Catholic teaching (Category C).[137]

Also in this section, there was a discussion of assisted suicide. The prohibition of assisted suicide is settled Catholic teaching (Category A). Church teaching regarding assisted suicide is explained in Directive #60:

> Euthanasia is an action or omission that of itself or by intention causes death in order to alleviate suffering. Catholic health care institutions may never condone or participate in euthanasia or assisted suicide in any way. Dying patients who request euthanasia should receive loving care, psychological and spiritual support, and appropriate remedies for pain and other symptoms so that they can live with dignity until the time of natural death. (Directive #60)

In sum, the threefold ethical critique based on the Ethical and Religious Directives has been applied to the topics discussed in the main sections of the chapter. The significance of this threefold critique as explained at the end of Chapter 3 and applied at the end of the applied Chapters 4, 5, and 6 is further discussed in the concluding chapter of the dissertation.

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Chapter 7. Conclusion.

This dissertation has discussed the contribution that the normative approach of the Catholic teaching can provide for resolving ethical dilemmas regarding medical technology.

The technology discussed ranged from what is currently available to what lies ahead for the future. First-class health care would not exist were it not for continual progress and innovation. Medical technology draws and adopts technology from many fields. Without technology, modern medicine would not have been able to accomplish the successful methods that are a blessing to mankind. The basics of medical technology that has made health care so proficient and quality oriented encompass a wide range of sophisticated systems.

The range of technology also promises a robust future for medicine. Technology continues to accelerate. The combinations of varying disciplines are converging to fundamentally change health care. The health care environment is changing at an unprecedented rate that challenges all to stay current with the "disruptive technologies." The technologies seem to reverse fundamental approaches existing previously. Revolutionary changes are occurring, forcing all to adapt.

With the rapid advancement in medical technology, significant ethical dilemmas emerge that challenge the established norms. Due to accelerated medical technology advancements, ethics is pressured to keep pace. This seems to be borne by the lack of research literature in the areas of reproductive, regenerative, and end-of-life medical advancement. This dissertation addressed the gap by considering ethical dilemmas in these aforementioned areas.

The dissertation analyzed the normative approach of the Catholic Tradition for resolving ethical dilemmas regarding medical technology. Specifically, the normative approach focused upon the Ethical and Religious Directives. The Directives maintain we have a human mandate that transcends all faith traditions and belief systems. The Directives state we have a social, pastoral, and professional responsibility to our fellow man. Thus, it is incumbent on us to aid in the correct formation of one's conscience in these areas of new and expanding medical technologies.

The significance of this dissertation pertains to the ever-accelerating pace of new medical technology and its impact on patient care. The Ethical Religious Directives provide a normative approach for resolving ethical dilemmas regarding pivotal breakthroughs in medical technology. The normative ethical approach has two components: a normative framework for Catholic health care ethics that adopts practical ethical principles as enunciated in the Ethical and Religious Directives (Chapter 2); and secular decision-making models in organizational and clinical ethics that are consistent the Catholic Tradition (Chapter 3).

Chapter 2 discussed the Normative Framework of Catholic Health Care Ethics. The Ethical Religious Directives are grounded on three leading concepts. These concepts of social, pastoral, and professional responsibility led the Ethical Religious Directives to develop several practical ethical principles for Catholic health care. First, the practical principle deals with the distinction between ordinary and extraordinary means. The second principle deals with the principle of double effect. The third principle deals with the principle of cooperation to address issues of complicity.

Chapter 3 discussed Ethical Decision-making Models Consistent with Catholic Ethics. This discussion engaged three related topics. To understand the significance of moral agency in organizational ethics, its characteristics and their connection with moral theories were examined. Ethical theories looked at the impact on health care organizations. This topic focused on clinical ethics and competency by examining the competency of the patient and advance directives. The fundamental concept in bringing decision-making of the patient to fruition is that of determining competency. These challenges reveal the crucial need for advance directives. The third topic dealt with clinical ethics consultation. An inherent relationship exists between clinical and organizational ethics. Thus an ethics infrastructure is an essential component of an organization's ethics integration and strategy. The ethics infrastructure links fundamental processes in clinical practice to the mission and core values of the organization. Accomplishing quality and professionalism is a key to success of the ethics consultation. Finally, an integral part of an ethics consultation is the creation of a patient case analysis.

Chapter 4 then applied the Ethical Religious Directives to consider Reproductive Technology. The first topic explored the embryo and personhood status. The prenatal status of the embryo, personhood, and the ethical framework were discussed. This discussion on the personal or “ensouled” status of the human embryo raises significant ethical issues for stem cells technologies and in vitro fertilization. The relevance of personhood, the issue of resourcing of stem cells, and the issue of using in vitro fertilization for the embryo’s health were reviewed. The discussion on the personal status of the embryo and its relevance for stem cell technology connected with the ethical debate on prenatal testing. This is a crucial aspect of the ethics of reproductive

technology that involves scrutiny of the availability of testing and interventions and the implications for tomorrow's children. The final topic focused the pivotal ethical debate on prenatal screening and concerns about screening consequences.

Chapter 5 then applied the Ethical Religious Directives to the area of Regenerative Technology to raise the crucial issues of genetic enhancement, germline modification, mitochondrial DNA, and gene editing with CRISPR. First, on genetic enhancement, two core concerns were explored: the significance of genetic enhancement for human progress, and the impact on future generations. Second, the ethical debate on genetic enhancement in general leads to the more specific focus on genetic germline modification that requires examining mainstream religious perspectives and also secular perspectives. Next, two recent technologies have emerged that were considered in further detail: mitochondrial DNA and gene editing with CRISPR. The science and the ethical, social, and policy consideration or religious concerns of these amazing technological breakthroughs were discussed.

Chapter 6 then applied the Ethical Religious Directives to technological concerns on death and dying by examining three related topics: changing attitudes towards death and dying, medical futility, and the withdrawal of life-sustaining treatment. First, there was a discussion of the changing attitudes towards death and dying, the characteristics and philosophical approaches. Second, this discussion offered insight into the ethical debate surrounding medical futility by examining the debate regarding the meaning of futility and the compassionate goals of medicine. Third, there was a discussion of the ethical debate around the withdrawal of life-sustaining treatment by engaging two related topics: medically assisted nutrition and hydration the relief of suffering at the end-of-life.

The applied Chapters 4, 5, and 6 dealt with practical topics that integrated an ethical critique based on the Ethical and Religious Directives that was explained at the end of Chapter 3. The conclusion to Chapter 3 explained how the Ethical and Religious Directives are based on different approaches to Natural Law. The first approach focuses on the universal aspects of human nature. This approach is typically associated with settled Catholic teaching on morality. The second approach focuses on the person, presenting a dynamic and historical view of the human condition as contributors to God's creation. This approach is typically associated with using the Principle of Double Effect to apply traditional Church teaching in a flexible manner to changing circumstances. Arising from these two approaches to Natural Law, a third approach has emerged, combining the nature-oriented and person-oriented approaches to new dilemmas regarding emerging technologies that may require doctrinal development in Catholic teaching.

The ethical critique in the applied Chapters 4, 5, and 6, based on the Ethical and Religious Directives, was applied to the main topics of each chapter. The critique adopts the above approaches to identify three distinct categories. Category A dealt with settled issues in Church Teaching reflecting the Nature Approach to Natural Law. Category B dealt with controversial issues eligible for using the Principle of Double Effect reflecting the Personal Approach to Natural Law. Category C dealt with issues requiring doctrinal development in Catholic teaching to address new dilemmas regarding emerging technologies. This threefold critique based on the Ethical and Religious Directives can provide guidance for Catholic health care to address emerging technologies in medicine.

In other words, the theoretical analysis in the dissertation is aligned with a practical ethical critique to guide ethical analysis in Catholic health care.

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