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Enhancing Quality Ethics Consultations in Pediatric Medicine

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ENHANCING QUALITY ETHICS CONSULTATIONS IN PEDIATRIC MEDICINE

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Duquesne University

In partial fulfillment of the requirements for

the degree of Doctor of Philosophy

By

Ariel Clatty

May 2018

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ENHACING QUALITY ETHICS CONSULTATIONS IN PEDIATRIC MEDICINE

By

Ariel Clatty

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ABSTRACT

ENHACING QUALITY ETHICS CONSULTATIONS IN PEDIATRIC MEDICINE

By

Ariel Clatty

May 2018

Dissertation supervised by Dr. Gerard MaGill

Medical ethics consultations occur predominantly in the adult realm of medicine, alternatively in Pediatric Medicine there is a widespread lack of training and skilled professionals to service these requests. Most of the literature in pediatric ethics consultations revolves around mirroring adult ethics consultations. This dissertation seeks to identify and address the issues related to quality of ethics consultations in a clinical setting regarding the organizational and research settings for Pediatric Medicine, and how adopting and applying the guiding standards for ethics consultation using the Core Competencies of the American Society of Bioethics and Humanities will better assist all parties to converge to a mutual beneficial outcome.

Organizationally, the relationship between the educational and knowledge based competencies increases awareness within the system to create an ethical preventative healthcare

culture. Promoting ethical reflection and creating a culture of ethics may serve to prevent ethical dilemmas or mitigate their effects by implementing a quality ethics consultation service.

The main ethical dilemmas concerning pediatric consent and assent are: concept of futility during end of life care, ethics of care with surrogate decision making, neonatal genetic testing and stem cell treatment. Not only are these debatable topics, these areas in pediatrics are part of the new age of clinical ethics consultations.

Research ethics involves dignity, respect, and basic human rights. Research is multicultural and differing in all societies. The quality of ethics consultations in the research setting of pediatric medicine is a need in research ethics both nationally in the US and internationally. Creating a program where all these consultative avenues are reviewed, modified and updated regularly to our ever changing societal norms, ethics consultations will be the tool to provide education and assistance to medical staff. The success of the ethics consultations in an organization will ensure the methodology will grow and support the changing environment and prospers within the health care system.

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Chapter 1: Introduction:

Though ethics consultations occur extensively in Pediatric Medicine, there is widespread lack of training and skilled professionals for these endeavors. Hence, a great deal of work is needed to enhance quality in pediatric ethics consultations. Pediatric Medicine is very different from adult medicine because of the focus on the best interests of the young patient (in contrast to the focus on autonomy of the adult patient). This focus requires a distinctive method of collaborative care between clinicians and the family.

Most of the literature in pediatric ethics consultations revolves around mirroring adult ethics consultations. Certainly, there is literature that assesses the risk benefit analysis and best interest standards regarding pediatric patients. However, typically this literature deals with narrow clinical issues that arise regarding patient care, especially at the end of life. Increasingly, those clinical concerns need to be interwoven with concerns regarding the organizational setting and the research setting of Pediatric Medicine. To address this significant gap in the scholarly literature and in the practice of Pediatric Medicine, this dissertation seeks to combine the issues related to quality of ethics consultations in the clinical setting with the organizational setting and the research setting of Pediatric Medicine, adopting and applying the guiding standards for ethics consultation in the Core Competencies of the American Society of Bioethics and Humanities.

Clinical ethics consultations serve as a quality measure in healthcare systems. These services not only provide consultations, but also foster education for clinical staff, researchers and promote ethics standards for healthcare policy. This dissertation applies discourse on ethics consultations to Pediatric Medicine. Not surprisingly, Pediatric Medicine raises distinctive issues for ethics consultation that in turn contribute to quality of healthcare.

The thesis of this dissertation is that enhancing the quality of ethics consultation should contribute significantly to pediatric healthcare. This thesis involves applying the established standards for quality in ethics consultation to the pediatric arena. This is done in the following manner. After the Introductory Chapter 1, Chapter 2 presents a critical summary of quality in ethics consultations as established by the Core Competencies of the American Society for Bioethics and Humanities (ASBH). Chapter 3 sets the landscape for applying these standards by delineating pivotal ethical dilemmas regarding the integration of clinical, organizational, and research ethics in Pediatric Medicine that typically elicit ethics consultations. The subsequent three chapters then apply the standards of the ASBH Core Competencies to foster quality in ethics consultation in the organizational setting of Pediatric Medicine (Chapter 4), in the clinical setting of Pediatric Medicine (chapter 5), and in the research setting of Pediatric Medicine (Chapter 6). The final Chapter 7 presents the dissertation's conclusion.

Chapter 2: Quality in Ethics Consultations in U.S. Healthcare:

Chapter 2 explains quality standards in ethics consultations and core competencies. Quality standards will be brought to the forefront by understanding what bioethicists are and the preventative ethics outlook on ethics consultations. Core competencies will be explained through ASBH core competencies and applied to Pediatric Medicine.

2A. ASBH Quality Standards in Ethics Consultations:

ASBH competency standards are held at the utmost regard to produce quality ethics consultants that can implement ethical theory, core competencies, and the standards of an ethics consultant's role. The critique of the ASBH core competencies will be developed more in surrogate decision making, patient valued care, care ethics and patient autonomy with

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development of ethical framework. This development ideally leads to the preventative ethics and the embodiment of organizational culture.

ASBH standards for ethics consultations have been standardized for decades. Implementation of quality ethics consultation services will initially highlight the need for consultation services, the calculations of trend decrease in readmissions, a lowered conflict rate, and higher quality adapted medical care that will in turn decrease costs. This approach can be seen through proper ethics documentation. In the end, the outcomes ensure value based care and a competent medical staff.

2.a.i. Healthcare Ethics Consultants Role:

To create an ethics consultant, one must first understand the role. This is seen through staff competence of ethics and what it can do for them. Most medical staff do not see the pertinent knowledge of ethics to patient care. Once certain ethical theory is ascertained by medical staff, then they too will be able to acquire new skills and knowledge that can be applied to everyday care of their patients.[1] The ethics consultant will be able to participate in the multidisciplinary care team that will help determine the wishes and values of the patient to properly direct their future in medical care. By allowing the ethics consultant into the clinical team setting, they will be able to help identify the ethical practice, decision making skills, core competencies, and ethical knowledge to embrace all aspects of ethical practice to ensure the most valuable care for patients.[2]

A clinical ethics consultants' role in the healthcare field is to develop and maintain the values of the institution by interpreting their mission along with the patient's wishes and goals to create an environment that constitutes quality driven care. These consults result from ethical conflicts that are derived from diverging views of how patient care should be conducted. New

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age medicine is not linear, and ethics consultant's roles are to detect the conflict at hand. Consultations for clinical ethicists are usually requested for multiple reasons, but mainly consist of matters of withholding or withdrawing treatment, surrogate decision making concerns, autonomy issues, end of life care, cultural or religious issues regarding care and treatment, professional responsibilities, and resolutions of ethical conflict.[3]

The conflicts that typically reside in clinical ethics situations usually deal with autonomy patient rights issues, beneficence of the caregiver, tensions between justice and autonomy or self-interests.[4] The consultant can differentiate between ethical issues or conflict, moral distress, patient satisfaction, or family disbelief rather than entertaining non-objective "ethical" ideals. The role of the ethics consultant can thrive based on normative theory, principals, and the core competencies that are morally justified through right and wrong so one takes the right action to manifest quality care.[5]

Whether the medical care is centered individually on the patient, there may still be conflict. This can emerge when patients, surrogates, or clinicians differ in the goals of care for a patient.[6] Some professional staff may not be equipped with the skills or competency in conflict management to appropriately handle the situation at hand. The effective assessment and interpersonal skills alongside negotiation, facilitation, counseling, advocacy, mediation, and debriefing are all required to be competent in conflict management situations.[7] Ethics consultants would be able to resolve conflict, and debrief staff on how to handle a current situation and similar situations for the future.

2.a. ii. Preventative Healthcare Ethics:

Preventative ethics is carried out by the implementation of academic nomenclature to improve the status of perceiving the need for structure, process, attitudes, and a process of

medical education to improve medical care.[8] The role of preventative ethics will not be economically based; it must rather be designed to prevent one from further harm or further possibility of increased chronic healthcare conditions. Preventative ethics provides healthcare systems continuous quality improvements based upon the system's performance, team compositions, proficiencies, and identification of ethical issues throughout the system whole.[9]

The organization's culture plays the role in preventative ethics based upon the moral obligations and values that the institution upholds for everyday care. The commitments of the clinical staff foster the act of "what should be done" for quality healthcare based upon the moral convictions of the organization and the values fostered within the systems.[10] The relationship between preventative medicine and the healthcare organization will be solely dominated by the moral stand of the healthcare workforce and the individual determination of moral duty to their patients. The dominant valued culture between staff and its organization can thrive based upon embedding values, beliefs, and ethical norms for a more cultivated quality care.[11]

Reallocation of resources to physicians and clinical staff members is pertinent to the survival of preventative care medicine.[12] By requiring staff surveys, quality feedback can achieve and promote a quality improvement plan by facilitating preventative ethics in medicine. Nursing staff can play a critical role within the preventive ethics improvement model because their professional knowledge of unit function, identifying unit based patient conflicts, and unit resources will be key to implementing a preventative ethics approach per patient unit based population.[13] By implementing a preventative approach such as: appropriate physician consults, coordination of care, effectiveness of treatment plans, patient feedback, and cost effectiveness, all these approaches will improve the healthcare delivery system.[14]

In the United States alone, the intensive care units account for twenty percent of inpatient costs that may be reduced by an ethics consultation of a trained, and experienced medical ethicist.[15] The cost for caring for patients in the intensive care units now accounts for a total U.S. healthcare cost of thirty-eight percent.[16] The relative information of cost reduction, preventative ethics, and surveys conveyed will better assess staff needs for ethics consultation. By relaying this information to clinical staff, improvements to produce a quality productive healthcare organization that benefits both the patients and the hospital system will assemble. An ethics consultation service can help resolve the ethical conflicts, produce preventative services, and help resolve conflicts that result in less undesirable days in the hospital system.[17]

2B. ASBH Core Competencies for Ethics Consultations:

The core competencies for ASBH involve particular competencies for an ethics consultant to be an expert and recommend particular ethical suggestions to proceed in clinical care. These recommendations are based upon proper knowledge of ethical literature, framework, standardized care, ethical duties, responsibilities, and actions based up ethical theories and practice in ethics. These will be more defined through a case based approach through core competencies and ethical framework.

2.b.i. ASBH Core Competencies:

The core competencies not only are one of the most important ethical approaches and foundations to ethics consultations, but also provide knowledge of ethical guidance to properly train newly developed ethics consultants. These consultants should have knowledge of consequentialist, non-consequentialist, utilitarian, Kantian, Communitarian, nature of ethics, Deontological, and human right approaches to apply ethical or theoretical foundation in supplying validity to their recommendation.[18]

The core competencies are extremely active in a case based approach. The value based approach that should be used in clinical ethics consultations should satisfy the patient's intentions, beneficial treatment, and long term success in their clinical interventions.[19] The value based care approach centers around these core competencies and states that ASBH rules clinical ethicists be involved in their patient's care. By doing so, the ethics consultation becomes patient and family centered and includes the collaboration of the healthcare team and partnership of the patient's values and medical innuendos as noted previously, but are supported now because they are done with the best interest of the patient because all are involved with obtaining the patient's goal.[20]

This basis of care approach and best interests' standards only thrive if staff are competent in ethics. This way medical ethicists can give an ethical analysis and document the ethical contraindications of a clinical case so staff members in turn can learn about ethical conflicts, dilemmas, and conflicting situations. The professional clinical staff should have certain specialized criteria that should be required to demonstrate continuing competencies and educational credits.[21] A proactive approach to ethical conflict for clinical staff would be to shadow or witness ethical cases and learn about the development of ethical issues so they are further aware and able to appropriately act on the ethically grounded protocols that have been set forth by accredited programs.[22]

The core competencies set a level of competence in ethics that requires an ethicist to be able to communicate, negotiate, recognize, demonstrate, and distinguish quality improvement skills to circumnavigate constrained behaviors in ethics consultations.[23] Being able to use core competencies and skills allows for an easier consultation based upon formal ethics training and ASBH guidelines. ASBH core competencies have set the standards for ethics consultations, and

have evaluated the methods and tools needed for a quality ethics consultation efficiency and efficacy.[24]

2.b.ii. Core Competencies Applied to Case Analysis:

To assertively assess a clinical case in which an ethical conflict presents itself, the ethics consultant must have the ethical assessment and analysis skills to competently analyze the ethical implications at hand. These core skills would be to gather all relevant information, distinguish which details are ethical and which are more relevant for another clinical team, articulate ethical concerns, identify beliefs or values of the patient, clarify ethical concepts, codes, or standards to evaluate all possible outcomes that the situation could ethically be permissible based on patient's goals of care.[25] Then the ethics consultant can make recommendations consistent with the ethics framework and can resolve the conflict at hand by discussing among the ethically acceptable options.[26]

Ensuring case analysis is properly critiqued, the ethics consultant should identify the ethical issues by relating the ethical methods and competencies to derive a normative method for the ethical implication at hand.[27] They can derive ethical expertise into real-life clinical practice. The role of the clinical ethicist can develop and maintain the ethical practice of ASBH standards and core competencies and focus on the responsibilities of the knowledge and skill for developing an ethics program or newly engaged ethicists.[28] The clinical ethicist uses the moral competencies to teach moral theories and philosophies of ethics in real-life situations.[29]

Through the previously stated core competencies, the case analysis of pre-term pregnancy. This case involves a child that needed resuscitation and ventilation upon delivery that resulted in cerebral palsy. There is a larger picture than the original diagnosis at play, and an ethics consultant must differentiate between the disorder itself, and dive into the conflict of one

parent wanting to withdraw treatment and one parent wanting to save their child's life. The ethics consultant in this case would be able to access the problem and process the information to give a clearer more concise decision on the ethical issues arising.[30]

Documentation is mandated for essential reasons such as: assessing, evaluating, and implementing care for patients for the quality of care to be managed between clinical care teams, and for legality issues.[31] Ethical framework and theory can flow between the documentation, assessment and plan of care throughout the patient's medical stay. This way ethical competencies and actions guide the plan of care and can give proper ethical knowledge to clinical staff through documentation in the patient's chart. Once ethical guidelines and competencies are documented in the patient's chart the value of the chart data can be used for reimbursement, performance measurement, and data.[32]

The approach to clinically coding ethics consultations for cost based analysis has yet to be done. The RVU, metrics that physicians use for payment is based upon their allotted time spent with patient's, procedural costs, academic productivity, and or clinical workloads.[33] The documentation of an ethics consultation should include the request, the data collected, and the recommendation to charge over and above salary, which most departments do not do use now, but should be a possible development for future consultation services.[34]

Chapter 3: Core Ethical Dilemmas in Pediatric Medicine:

Chapter 3 discusses the ethical dilemmas concerning pediatric consent and assent along with the concept of futility during end of life care in pediatrics. This chapter will develop these concepts to better understand the pediatric relationship needed between the medical team and family during difficult situations.

3A. Respecting Family Consent and Minor Assent:

Pediatric Medicine differs from adult medicine based primarily on one point; this concerns the concept of consent. Pediatric patients cannot consent to medical procedures, but they may assent to medical care. These concepts will be further developed in this section.

3.a.i. Patient's Rights and Paternalism:

The patients' rights movement was a difficult movement to generate.[35] Most patients are too transitory to feel fully involved in the process and some would rather forget their time in the hospital.[36] However, this movement would be the key for striking the development of the organization for the protection of patient's rights: The National Welfare Rights Organization (NWRO). The NWRO completed twenty six requirements in order to protect patient rights.[37] In 1972, American Hospital Association approved the Patient Bill of Rights that disclosed patients to their privacy of all medical information, explanations of their bills and medical treatment, and lastly it also included many other atomically appropriate rights.[38] Some physicians saw this bill as a sign of doubt between their relationships with their patients.[39] All in all, the outcome of these organizations is for the good of the patients. Patient's rights spiraled into a new era. Physicians, health care providers, and patients were seeing how to interact with each other to meet the common goal of autonomy and patient avocation or benevolence. The Golden Era of American Philosophy was being shaped.[40]

Paternalism is the affirmation that doctor knows best and making decisions without involving their patient in their own care.[41] Patients and physicians have the responsibility to each other to have an open dialogue with respect to one another. [42] The physician in paternalistic acts may seem to be non-beneficial in terms of morally respecting the patient's wishes. The patient may want one thing and the physician will do another. The patient's wishes are supposed

to be held to a higher standard and the physician should do everything in their power to respect and carry out those wishes if medically possible.[43] Their duty is to the patient who should benefit without their wishes being overridden. Paternalistic acts may not be noticed at first because they are in the form of deception, lying, manipulation of information, and coercion.[44]

3.a. ii. Minor Assent and Autonomy:

There is no specific age that a child can legally consent other than when they reach the age of eighteen to which they are considered a legal adult. Most researchers see that at the age of fourteen or fifteen, children have enough knowledge and understanding to assent to medical decisions.[45] There is always the problem of asking too much or too little of children.[46] Children either can be asked to make decisions, but they will be overwhelmed and not intellectually ready to make their own decision or children can make an intellectually developed choice, but never be afforded the right to make the decision because they were denied the opportunity to decide for themselves.[47] There is this fine line that either inhibits authority of choice or denies that right. As children develop through their childhood they should become guardians of their own decisions and take the responsibility off their parents.[48]

The early stages of childhood, which include the ages of two and three, make it difficult for a child to assent to pediatric care. The bracket of ages six to nine have more knowledge and can ask more questions to be more involved in the decision-making process.[49] Through questions between the physician and child the age bracket of seven to nine showed promise of having knowledge about their care and could understand the risks and benefits of their decisions.[50] Their decisions are based on a certain understanding of medical terminology, when an adult's understanding of medical terminology is slim to none. It more so depends on the physician's determination to relay the knowledge of what they know to the patient in a way that

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they can understand it. There is no systematic way of knowing an age that a child can

understand the medical information given to them.[51]

3B. End of Life Care in Pediatric Medicine:

Futility and inappropriate treatment play pivotal roles that are backed by new goals of

medicine which will be explained further alongside clinical judgment and perspectives of each

topic. Most religions view futility or certain treatment options in varying dimensions of

acceptance. Christianity, Judaism, and Catholicism consider futility at different angles, but no

matter what religion the patient is, the care will always be set at the highest quality.

3.b.i. Futility vs. Inappropriate Treatment and Goals of Medicine:

End of life care is full of choices. This grey area of morally righteous choices derives

from the new goals of medicine. The line between living and dying is part of that grey area and

knowing when to stop treating a patient is part of that unknown.[52] Futility is the concept of

treating, but only to find that these measures are useless, or futile. The notion of futility

denounces efforts to sustain life even though by prolonging life the life that is prolonged is not

meaningful and has no purpose.[53] The obligation of the physician is now to treat only when the

benefits outweigh the harms, and to not offer treatment if the treatment is ineffective.[54]   The

moral logic and theory around this perspective captures the understanding of whether a physician

ought to do something and if it is impossible then there is no obligation to attempt it.[55]

Traditional goals of medicine and considerations of care included saving and extending

life and to also relieve pain and suffering.[56] Life is and should be of value and essentially last

until the longest possible point, per most medicine. Inappropriate treatment may be administered

by the convenience of the physician or family rather than inexplicitly defining it as medically

inappropriate.[57] These cause distressing situations for staff and family. Debriefing sessions will

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decompress all the stressing emotions, fatigue, and compassion disconnect from patient care that will allow for validated support and solidarity among team members and the organization.[58]

A patient's well-being and integrity is now an integral part in the care of the patient at the end of life.[59] The considerations taken at the end of life is mainly based on integrity of the person, the compassion of the doctor, and the technology of medicine. The integrity and respect of the patient needs to stay intact during the whole process of end of life decisions, whether those decisions are to preserve or end life is up to the patient.[60] Respect of the patient is earned through the compassion of the physician. Pain and suffering is temporary in the end game; this is monitored and managed, but the only loss in end of life care is if the patient loses their dignity and respect because no such dying can harm a good life lived.[61]

3.b. ii. Comparative Religious Perspectives:

Physicians need to appreciate the values of their patient's wishes if they are based upon religious perspectives. Many patients and or families who come into the hospital setting, and especially in end of life cases, look towards their religion hoping to find answers.[62] Physicians should respect the patient's and families' views, and rather than criticize their decision making, they should look towards providing comfort by mobilizing spiritual support systems for the patient and family.[63]

During end of life care, many religions have differing views. There is this hope that God can make a miracle, and that this faith is their support system to determine if care is futile.[64] Physicians at this stage may find it difficult not to intervene in spiritual decision making. However, if the patient is faith based and wants specific wishes carried out a certain way, then the physician and medical team must respect those wishes. The physician's main wishes, as all doctors, is to relieve pain and suffering to their patient, and that response is a goal of medicine

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that is hard to ignore.[65] The physician-patient relationship at the end of life and during general care is important because understanding the patient's wants will make end of life an easier, less painful death for the patient and family. Understanding and addressing these concerns nearing the end of life allows the respectful comprehensive end of life care to be carried out in a compassionate spiritual way.[66] The differing views of religion need to be acknowledged and understood by the physician so the proper care is carried out and not deemed the lowest priority, because to most people at the end of life this spiritual awareness is heightened.[67]

4. Ethics Consultation Quality in Organizational Setting of Pediatric Medicine:

Chapter four accentuates the understanding and need for ethics consultations in the organizational setting. It will discuss organizational culture, moral agency, professional conflicts, patient safety and conflicts that arise in pediatric consults. The quality standard for ethics consultations on the organizational level is a high standard for the organization to withstand organizational defeat.

4A. Organizational Moral Agency and Culture of Quality:

This section will define the organizational culture of healthcare industries along with the professional conflicts that may arise among the ever so competitive healthcare world.

4.a.i. Organizational Culture:

The moral agent of every organization is ascertained by the culture of the healthcare system and the way the system is run. Culture of an organization can also be related to the character of the organization.[68] This character just like an individual's character relates to the traits of the company. An organization's ethical climate or culture is what the organization's ethical standards and procedures are for that system and how they address ethical problems and issues that arise.[69] An organization's ethical culture is how an organization's moral agency is

defined. Moral agency is the investigation of institutional culture to understand how an organization makes their decisions and whether those decisions have greater benefits and harms or manifests goods throughout their interactions with other institutions.[70]

Health care organizations set goals, apply standards to meet their goals, assess their goals and are judged by their goals. It is not an easy task to develop missions, values, and organizational goals. However, if an organization fails to meet the standards of their own mission to their company, then their organizational ethical components have been flawed.[71] The organization's culture needs to be in line with the values, mission, goals, and vision of the company in order to carry out the standards of the company's moral agent.[72] There is a duty of every individual within an organization to individually challenge their own personal moral agent and to be in line with the ethical moral agent of the company. An organization's moral agent or in other words the definitive decisions the company makes should support the best ethical practices to invoke their moral worth and to strive for excellence.[73]

4.a. ii. Professional Conflicts in Research:

Funding for medical research can create conflicts of interest between parents, children and research foundations. Conflict may also arise during the explanation of consent or the autonomous pediatric structure. Children may refuse care and physician's need to balance autonomy and respect their decisions even if parents do or don't see it as the proper decision.[74] If the patient is not able to give fully informed consent or desired notion of care, then there should be other avenues pursued in order to respect their feelings, personal beliefs, and demonstrate the understanding of their wishes.[75] Most patients and parents would like to be informed to the fullest extent in order to participate in a research study. If the patient and parents are also informed of the financial conflicts of interest in the research studies, then they are more willing

to participate even though there may in fact be a conflict of interest. The research subject and parents are more inclined to participate in the trial if they are told that the company funding the study is also the company that produces the drug.[76] The research study would be deemed unethical if the information of the research study was not properly produced during the beginning conversations of the medical research study.[77]

4B. Quality and Patient Safety in Pediatric Medicine:

Quality and patient safety are and should be considered a high standard when it comes to Pediatric Medicine. Childcare and its consistent quality is a necessity of prime importance that every institution should value and respect.

4.b.i. Patient Safety in the Organization:

Healthcare is complex; the system alone is comprised of many differing elements inter-acting in a variety of ways that need to coexist. They need to reasonable an atmosphere to provide the necessary care to patients.[78] Adding to the complexity of healthcare is the aspect of patient safety. Patient safety can be defined in many ways; it is considered the umbrella of care though it truly fits within the realms of quality of care. Patient safety can be defined as the avoidance or prevention of harm stemming from preventable acts rather than errors after the occurrence of the accident.[79]

The idea of culture and the organization's values are instilled into the work of healthcare providers. The organization should be set up to deal with the outcomes of patient risk, errors, and quality in their care.[80] Safety culture embeds the embodiment of the organizations culture to intertwine the attitudes of the healthcare providers' behaviors so they flourish.[81] To improve organizational culture, efforts need to connect staff and the organizations policies and goals in harmony to excel in care. The culture of the organization is not only difficult to measure but it is

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also viewed as a low ideal on the list of fixing patient safety.[82] Even though culture is listed as last to fix patient safety, culture of the organization can enhance the quality and safety of the organization through the attitudes of the healthcare staff. The attitudes of the healthcare providers are vital during patient care because determining the patient's needs are crucial for the quality of their care.[83] The attitudes of the physicians spiral from the culture of the organization. Usually the people working for the organization have the same morals and values within the organization itself. With the right safety culture and the right attitudes of the providers, safety and quality of care can flourish.[84]

4.b. ii. Conflicts and Pediatric Consults:

Conflict is usually what drives pediatric consultations.[85] There are three parties that are involved during pediatric care: the patient, the physician and the family. Since this is no longer a strict relationship between the physician and the patient, the triangle of needs and wants is a little harder to circumnavigate.[86] Pediatric ethics consults tend to be driven by conflict and is the most common reason for consultations.[87] Value ethics is an everyday practice in Pediatric Medicine. The values of the patient, family, and physician need to be understood to put the best interests of the patient at the top of the addressed issue list.[88]

Consultants need to explore the values of the physician, patient, and family as a team of the top priorities because these values are what drive the goals in medicine.[89] Values are what make the patient or family drive to the conclusion that they deny or accept certain aspects of medical care. Values also drive physicians to stand by certain aspects of medicine. This is where ethical conflict can occur because neither party may see the other side's argument.[90] The clinical consultant must then see where the true values lie, or the intended fate of the patient may not be in their best interests. Each party however, has their own views of the situation. This

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entails further information, and the understanding of everyone's values during the time of the consultation.   Pediatric patients need to be involved in their care to the best of their ability, and the parents need to be informed during the process of their child's medical situation to collaboratively make decisions resulting in optimal care for the child.[91]

4C. Child Maltreatment Situations: Non-maleficence & Justice:

A hospital system has a duty to their patients to protect them of endangerment or harm. In a pediatric setting, this case is even more prevalent for little humans that are vulnerable, and not able to care for themselves. The organization's culture and proposed didactic training in child abuse scenarios should be identified and updated for the staff's competent knowledge when faced with an abusive situation. Several studies done on child maltreatment consist of risk indicators for physical abuse and neglect which include: recent life stressors, low maternal education levels, substance abuse, low maternal age, parental death, and sociopathic behavior.[92] Most of the time these situations cause professional conflicts within the role of the clinical physician to bring justice to the patient or to only focus on the current medical situation at hand.

4.c.i. Non-Maleficence vs. Justice & Role Disarray of the Clinical Providers:

The organization's culture in the cases of child maltreatment should adhere to the standards of non-maleficence and justice to guide the practice of medical care ethically and appropriately for the best interests of the child patient.   Non-maleficence is a vital principal of medical ethics, but it also encompasses beneficence and the respect for autonomy because the patient's interests should always come first.[93] The organization's culture should exude non-maleficence in the sense that all medical staff should do no harm to their patient. As physicians, they inevitably do initial "harm" to the patient or induce pain to provide a net medical benefit to the patient with minimal harm that is encircling beneficence and non-maleficent treatment.[94]

The conflict of non-maleficence and justice in a child maltreatment setting is whether the standard of best interests holds true because the best interests taken to hand may be of the parents rather than the patient. However, in a medical situation, a child's best interests should not be superseded by the parent's interest to mistreat the child patient at hand and have their interests beneath that of the parents.[95] When a child presents at the hospital for any type of condition and thoughts of possible child maltreatment are also present, it is the duty of the hospital organization to act in accordance with the child's best interests, hospital standards. It is the moral duty of physicians. The hospital administration and physicians are not required to uphold parental refusals based upon religious convictions, neglect, abuse, or child endangerment.[96]

The principle of justice holds true to this. There is a sense of duty to protect the vulnerable, the weak, and the mute, but it is hard to draw a line when a physician takes their responsibility as a justice leader over being a medical provider. To a child, that white coat can represent their own super hero who is there to save them when they may not be able to save themselves. The physician is their own detective and advocate for their patient. The principle and act of justice should be an act of protection within healthcare and especially in pediatrics. A medical system that defines themselves by ethical practices and values embodies the principles of justice and non-maleficence into the relationships of medical personnel and patient care.[97]

Physicians have a duty to their patient to assess their medical needs, and at the same time they are mandated reporters, however, when are they a physician and when are they to act as the police? They are the physician always, but they may need to be more authoritative on aspects dealing with child maltreatment. Professionals should address the trauma histories of the child patient to improve their patient's personal well-being and the profession's efficacy.[98] The medical evaluation versus the duty to be a mandated reporter could become conflicted if a

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physician oversteps their medical knowledge to justice of the peace. The medical evaluation of suspected victim of child abuse should be based upon specific screening criteria conducted by a trained specialized medical provider.[99] Maltreatment is any physical, sexual or emotional abuse along with neglect of a child.[100] Physicians should report the incidence and discuss these situations with qualified regional child abuse consultants and child protective services so that legal action is not taken against them.[101]

However, it is unclear as to whether a physician should always inquire about abuse, or take matters into their own hands to diagnose certain issues that may have nothing to do with child abuse. It is important to protect the child, to reduce their suffering, but it is also important to confirm the reasonable suspicion of the abuse to make proper medical decisions for the patient's care.[102]

4.c. ii. Obligations to Child Patient by Setting Ethical Standards:

When a healthcare organization interacts with child abuse situations of any notion, it should recognize, report, and try to prevent the situation from ever happening again. The safety of the child in these cases, should not be taken lightly. The organization and community's efforts should be focused on the child patient safety efforts that are in place to serve as individualized care that can identify and react to certain risk factors.[103]

Child advocacy should already be a primary value in a healthcare organization and the people that work for a children's institution. Prevention of further abuse should be evidently convincing based upon the skills to recognize and report the act of child abuse. This said, the avenues of prevention should start with the physician, and healthcare organization, alongside the community and government to ultimately lower the chances of long term child abuse prevention.[104] Children in such a vulnerable state may not confide in these tragic memories of

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abuse nor may they make sense when telling their story of abuse. They just may not have the vocabulary to explain what occurred. Proper education for employees and the organization will add to child advocacy and patient safety. The organization along with society cannot improve the justice system alone, the preparation and continuing education of child abuse should be maximized by all efforts and the child patient should have credibility and advocacy on their side.[105]

Physicians may experience a role conflict when treating child patients of child abuse situations. On the one hand their a physician, and on the other they are a forensic scientist, an advocate of justice, an interviewer, and a mandated reporter. These two roles may have internally conflicting emotions that may interfere with patient care, even though the physician is trying to do right by the child patient. The ethical problem that presents itself is whether the physician should make the dual role necessary.

Physicians may internalize emotional or moral distress in these temperamental situations. Learning to have specialized teams to deal with these distressing situations will help coordination of care and ultimately the emotional status of staff members. These situations are difficult and not easy to process, but healing the emotional needs of medical staff should also be peril to medicine and ethics of child abuse situations. It is imperative to try and find balance in ethics and medicine so that the social didactics between patient and physician are justified and regulated to achieve a common ethic for a moral physician autonomy in pediatric critical medicine.[106]

5. Ethics Consultations Quality in Clinical Setting of Pediatric Medicine:

Chapter 5 will discuss the ethics of care in Pediatric Medicine along with surrogate decision making. These two topics go hand in hand with the underlying theory of quality within

pertinent decision making. Neonatal genetic testing and stem cell treatment are two major areas to focus quality in the clinical setting. Not only are these debatable topics, but these two areas in pediatrics are part of the new age of medicine.

5A. Ethics of Care & Surrogate Decision Making:

The ethics of care will describe the understanding and meaning behind the quality of care involved in Pediatric Medicine. Surrogacy involving patients' parents will dive into the understanding of deciding what is best for the patient, and their best interests.

5.a.i. Ethics of Care in Pediatric Medicine:

The ethics of care model in Pediatrics is the understanding of a vulnerable patient that may not be able to speak for themselves. This is an agenda to construct a care plan for an individual that has never been able to promote personal values.[107] The theory of ethics of care pertains the driving factor of compassion towards other human beings and putting forth personal values, morals, and ethics in order to pursue the patient's best interest.[108] The idea behind care ethics is to take on the responsibility of the vulnerable and to adhere to their needs, and to be able to listen and engage in order to respond to those needs.[109]

This theory of care introduces the factor of compassion into the engaging relationship of patient and physician. The duty of all physicians is to have a basic level of compassion.[110] Every physician should attain or acquire a basic level of compassion during the full spectrum of care for their patient. For this new compassion in medicine to take flight, it must be presented to the public as the ethically central part of medicine.[111] All of medicine rests on this special relationship of the patient-physician relationship.[112] The relationship between doctor and patient is built upon trust. This trust was initially built upon compassion. Trust builds the gap between

the uncertainty of the patient and the physician.[113] In pediatrics, there is a three-man team. The parents, the physician, and the patient. The values of the patient may not be known, but the compassion from the physician, the trust in the medical care, and the parental decisions that ultimately have the best interest in the child patient creates care ethics.[114]

5.a. ii. Surrogacy & Best Interests in Pediatric Medicine:

The surrogate should act on grounds of knowledge. They should understand the patient and wishes of the patient. The surrogate decision maker must be competent to make reasonable decisions; possesses acceptable knowledge and information; must be emotionally stable and be dedicated to the patient's best interests.[115] There is a decision to be made whether a person is competent or incompetent. The physician and medical staff use their professional judgment in determining this decision. There is a fine line between competent or incompetent and there is no true person to decide this matter, but psychology tries their best to deem a patient competent or not. There is no test that exists to distinguish between an incompetent and competent person.[116]

The physician should however have the best interests for the patient at hand, especially if the patient is a child. Parents can weigh the risks and benefits before making a conclusion. Parents have the legal and moral authority to make the decisions for their children.[117] Surrogates are not the ultimate decision makers, and should always look toward the best interests of the patient, and not the interests of themselves. They are basing their decisions off what the patient would want, the values and goals of the patient and what is in their best interest. There needs to be a clarification of the role of surrogate decision makers.[118]

5B. Neonates: Genetic Testing/Stem Cell Treatment:

Genetic testing and stem cell research are part of the new age of medicine. These genetic tests and stem cell research can break the barriers of medicine. They can aspire scientists,

researchers, physicians and the like to find cures for diseases that have befuddled all since the beginning stages of research.

5.b.i. Neonatal Genetic Testing:

A genetic revolution has evolved in this new age of medicine where mankind has surpassed the unimaginable, and invented genetic testing which engineering can foresee possible threats during different stages of birth. Genetic engineering is the manipulation of a gene, and gene therapy is the implementation of a sperm or egg intersecting the possible undesirable disease.[119] These new ways of genetic testing allows medicine and science to engineer new responses to disease and alter genes in a way to empower the stronger healthier cells.[120]

The old age tale of humans playing God, is not only an ethical debate of how far can we push medicine, but when will science be too empowering to mankind. [121] This new age of medicine should be walked within a set of guidelines. Genetic testing should progress with the future of medicine, but the ethical guidelines of healthcare should be a forefront driving factor when ensuring ethical procedures.[122] The United States has provided guidelines to ethical research, but even with these guidelines the medical research may still need higher quality assurance for the area of genetic testing. Problems in genetic testing are still occurring: some genetic tests are still not perceived as safe, effective or useful; there is no guarantee that these genetic tests meet a high quality standard before performed on humans; the informed consent process of genetic testing is still not always understood by patients and consenting adults.[123] There is a need for recommendations for genetic testing in order to have a safe and effective medical treatment plan for the people involved in enacting stem cell research.

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<u>5.b. ii. Stem Cell Treatment:</u>

In 1992, a couple scientists scientifically cultured the first embryonic stem cell in a laboratory.[124] The stem cell is the creation of a type of cell which can transform into differing cell types.[125] Stem cell research has been debated for over two thousand years, and the opponents of this debate see that an embryo no matter of how it became its own cell is a human.[126] This debate has stemmed from the position of determining when a human is a human. The dissection of the human embryo will still need to require the proper consent guidelines since researchers would be dealing with a pediatric human and an adult. ESCRO (Embryonic Stem Cell Research Oversite) Committees were formed to correspond with IRBs (Institutional Review Board) to better preserve volunteered medical research in stem cells.[127]

The National Research Act of 1974, established the IRB who proposed the notion on the Belmont Report which includes the conduct of medical research needs to follow a particular criteria of: informed consent, risk benefit analysis, and fair participant selection.[128] Some opponents of the Belmont report see that an embryo is neither a fetus or recognized as a human being.[129] Therefore, researchers would not need to meet criteria of the Belmont Report based upon the notion that the embryonic stem cells are not human subjects. Most medical research done on embryos are derived from the fertility clinic using the name "surplus human embryos" attained from the election of an abortion.[130] The debate stems from thousands of years of where and when medical treatment can take place, and what barriers for medical treatment upholds to the standards and values of ethical criteria.

<u>6. Ethics Consultation in Research Setting in Pediatric Medicine:</u>

The research setting in pediatrics is a touchy arena. This pediatric population needs to be protected and not just in the United States, but in a global perspective. Another subject in

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pediatric research ethics is the minimum harm criterion which creates ethical dilemmas during the research process in pediatrics.

6A. Protecting Human Subjects: Global Perspectives:

Research is multicultural and differing in all societies. The quality of ethics consultation in the research setting of pediatric medicine is a need in research ethics both nationally in the US and internationally.

6.a.i. Research & Multi-Cultural Society:

The ideal multi-cultural society allows every individual in that society to participate as an equal in the culture and the law.[131] Society has evolved, but the ideal multi-cultural society does not exist in the way that one would hope. The United States is a melting pot of cultures, religions, and economical arrays.[132] These differences create this society in which racial, economic, and religious differences deem advances in research as a difficult task.[133] Researchers, first, need to understand the individual they are dealing with. The researcher must illustrate or learn the meaning of the individuals' values, cultural belief, and respective ethical perspectives to conduct quality research in a multi-cultural society.[134]

It is the duty of practitioners to strive above the standard of cultural norms, and to respond the changes in demographics in research.[135] There is a challenge to develop a global culture of medical treatment and research that insures the patient to be respected.[136] The reason this is difficult to understand is because every culture has different forms of respect. A culture may have the chief of a tribe sign off on consent instead of the directly-involved individual. In some cultures, only the males may be the ones giving consent when the females do not have the same privilege. Cultural diversity is an ethical essential, undividable from respect for human dignity.[137] The respect for human culture and dignity ought to go hand in hand. These two

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concepts cannot be ignored. Human dignity is a part of every human being no matter what area of the world into which they were born. The respect for a human person should be a globally-known moral principle. This should never be thought to be a deterrent in medical research. Respect for human person, whether a child nor adult, should be held at the upmost importance, especially in human research.[138]

6.a. ii. International Research Ethics:

Bioethics can be used universally. The quality of ethics consultation in the research setting of pediatric medicine is a need in research ethics both nationally and in the US.   This framework of ethics and morals takes the basis of bioethics and expands it beyond everyone's boarders.[139] A global ethical framework includes the values human beings share with the basis of ethical principles.[140] Bioethics discourse can no longer focus only on the industrialized countries, but need to also focus on the developing countries under the bioethical frameworks continuation to grow.[141] This framework spreads to all areas of the world including these developing countries. Their cultural, traditional, and religious aspects may be different than those of the developed countries, but they should not be oppressed by the views of the power countries. The morals and values of all humankind should be universally respected.

The universal ethical framework also tries to concentrate on three main areas. These areas include: the drive to reduce health inequities; distributional justice; and the health of marginalized populations.[142] Health inequities are the unfair and detrimental consequences to communities that are connected to the laws that govern civilization.[143] Social justice remedies who receives global goods in which statistics show the individual level and the level of wealth in order to see the equality.[144] Lastly, the marginalized populations are cause for concern due to the discrimination, racism, and the continuous injustice of people.[145]

<u>6B. Minimum Harm Criterion in Pediatric Medicine:</u>

Pediatric research ethics will be explained in more detail, and provide a thorough understanding of the goals and achievements that will be reached through ethics consultations in quality of research. The minimum harm criterion is based upon the use of only minimum harm will be allowed for a research study to take place in Pediatric Medicine, and this will be further developed in this section.

<u>6.b.i. Pediatric Research Ethics:</u>

Young children enrolled in pediatric research pose many ethical questions.[146] Children participating in medical research may not always be achieving a benefit to themselves, they may be contributing to the health and well-being of adults or future children.[147] The child themselves need to consider what is in their best interests to involve them in stages of research that may not directly benefit themselves. Parents of these children also have the duty to protect their children and only involve their children for their best interest.[148] If the value of the contribution to research is exponential, and serves a higher value than any other project it may also have the rewarding factor of significant purpose to the child patient.[149]

The conditions that need to be met to conduct medical research in a non- beneficial study pertain to net risk allowance, risk threshold, and compelling justification.[150] If these conditions are met then the child and parents have the authority to involve themselves in these medical research projects. The Belmont report still encourages that if the conduction of research can occur on adults then the latter effect of older children to younger children can proceed as long as the condition of research cannot be conducted on adults for beneficial research.[151] Children participating in research can later appreciate the affiliation with medical research and be grateful to know that their data was part of a new treatment or discovery of a disastrous disease.[152] Much

of pediatric research can be considered speculation, and therefore needs to have set boundaries, criteria, and guidelines in order for proper ethical research to take place.

<u>6.b. ii. Minimum Harm Criterion:</u>

Many researchers base their findings on no benefit higher hazard pediatric studies. This no benefit means that the research conducted in most pediatric cases are for future children with the disease and not for children being treated with the disease.[153] These studies are a potential risk however for children with no benefit.[154] The funding aiding these research studies are funding research for the future benefits of children, but not benefiting the family or child of the current participant. The no benefit, higher hazard study should not represent more than a minimal risk for children in the study because these studies are advancing knowledge for future pediatric patients.[155]

There are two common interpretations of pediatric risk factors: absolute and relative standards.[156] The absolute standard recommends that children only undergo medical research that is normally involved in their everyday lives, or research that would be considered routine during physical and psychological examinations.[157] The relative standard chooses the subjects relative for the study based upon their daily life and the risks pertaining to their daily lives[158]. Participants in research must have all information for the research study presented to them because some research has net risk, which is the added risk the participant takes on that is may not have a compensated clinical benefit to the patient participant.[159] Any risks the pediatric participant is exposed to needs to be well critiqued and known before entering any agreement for the perceived benefit in research.

7. Conclusion: Educational Features for Ethics Consultation in Pediatric Medicine:

The Joint Commission of Accreditation of Healthcare Organizations has mandated that all hospitals across the United States have a system that can address ethical issues or conflicts in patient care.[160] This ensures that all hospitals have some type of service that is educated on how to deal with ethical conflict in medicine. However, most medical staff members are not equipped with this education nor know of clinical ethicists or ethics teams in their healthcare system that can help support the conflict at hand. Medical ethics curriculum needs to be developed through the structure of medical education in medical schools and residency programs. There is a hidden curriculum of values, and moral righteousness in medicine, however, there ceases to be a controlled perspective of structured principles, terminology, and goals of medical ethics in present-day curriculum lacking in acculturation and untouched ethic fundamentals needed to practice medicine.[161] There needs to be a stronger educational process for medical staff and healthcare systems for clinical ethics to thrive. Ethics consultation is a need. Ensuring ethics education throughout the healthcare system benefits all clinical staff involved with clinical conflicts.

The ethics consultants' role is changing immensely in the medical field.[162] The experienced clinical ethics consultant should possess the following qualities: be able to identify and analyze problems; be able to use ethical notions to solve the problems; communicate effectively to all medical staff; be able to negotiate between patient, family, and physicians; educate medical students, medical staff, and attending physicians how to prevent similar cases in the future.[163] Ethics consultants must give their recommendations and allow the other professionals involved the opportunity to discuss the basis for them.[164] Education is empowerment. Clinical personal will be able to learn, debate, and identify ethical triggers to

involve clinical ethicists. Prospering ethics consultation throughout the healthcare system will

not only provide a higher quality of care, but the benefits of the service exceed care limits and

ultimately, change medicine.

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Chapter 2: Quality in Ethics Consultations in US Healthcare:

Implementation of quality ethics consultations will improve quality standards and help excel core competencies in healthcare. With this type of implementation, the institution will be required to create a defined clinical ethicist's role in the particular healthcare system, and the consultant will be required to use their ethics background and training to implement ethical theory into clinical practice. Embodying these core values of ethics into the culture of the system will allow for a more conducive preventative practice of ethics in medicine.

This will be handled by calculating and assessing the success of an ethics consultation before and after admissions into the healthcare system. In the end, this will show system wide cost reduction, congruent care, and preventative medicine. The documentation of these efforts will be in the patient's chart for use during future admissions to continue the effort of consistent care, and ethics consultants will also be paid for their work from patient documentation in the chart just as physicians are paid from the RVU statistic calculations. The implementation of these clinical ethicists will allow for core competencies to drive healthcare in an ethical and progressive direction that allows for the culture of the organization to improve their own quality standards of their medical staff, organization, and patient satisfaction. These consultations will improve healthcare as a whole and will be shown through quality, preventative practice, cost reduction and implementation.

Pediatric medicine is theoretically designed from the framework of adult medicine and downsized for a smaller patient. Pain medication, therapies, and the application of these are developed for the most part for adults as well and mathematically adjusted to fit a child patient. This is not the same for ethics. Ethics is a complexity that derives from the core competencies, but then is depicted differently based upon an adult or a child patient. The need for pediatric ethics consultations that are focused around pediatric patients is dire. The adult realm of ethics

does not fit within pediatrics and there is quite a distinctive difference that involves proper ethics education in pediatrics to deal with conflict management issues. Pediatrics will benefit with the implementation quality ethics consultations to the effect of improving quality standards and curtailing care specifically to pediatric patients in healthcare.

American Society for Bioethics and Humanities, ASBH, has determined that certain core competencies are definitive for ethics consultations. These can be helpful and applied to case consultations and analysis to determine what is in the patient's best interests during their medical care or dissolving the ethical conflict at hand. Pediatrics is based in surrogate decision making and care ethics because unlike in adult medicine, where autonomy is one of the leading ethical frameworks, in pediatrics, neonates, children, and even teenagers do not have full autonomy in making their own decisions. Rather surrogates, in most cases parents and physicians, best decide what decision to make based on best interests rather than values in a child patient that have not been provided as in adult cases. Ethics is still being born. Staff competency and conflict management capabilities are not an essential demand when hiring nurses or other clinical staff members. Implementing quality pediatric ethics consultations will drive competent staff and best standards care approach to improve the care for pediatric patients, clinical staff members, and families during a crucial time for the child patient and all involved. This will be concluded through case analysis and quality ethics consultation service.

I. ASBH Quality Standards in Ethics Consultation:

The healthcare ethics consultant's role is important to understand when in a clinical setting. Alongside this role is understanding proper implementation of ethical theory to obtain ethical guidance in clinical conflict situations that arise. The role of the consultant and proper knowledge of ethical theory will drive quality consultation services. The documentation of an

ethics consultation is one of the most valuable and important steps. Physicians and clinical staff ask for guidance and without proper documentation, future care may be misguided and misdirected. The ASBH competencies and framework improves quality standards of values in healthcare and allows for ethics consultations to be quantified based on sole representation of ethical duty, and framework towards quality patient care. This in turn will prove to pay consultants for their consultations in the charting system like the RVU, relative value unit, system physicians use.

A. HealthCare Ethics Consultants Role:

These next sections will explain the role of the ethics consultant, implementation of ethical theory, documentation of ethics consultation, and possible costing approaches for ethics consultants.

I.a.i. The Role of the Ethics Consultant:

In order to create an ethics consultant, one must first understand the role. Clinical ethicists may have differing roles depending on the healthcare system within they choose to work. Some responsibilities an ethicist may hold may be to 1) articulate the ethical issues within the organization to the stakeholders in order to obtain the vision and values the organization holds as their mission for patient care, 2) have organization management of cultural values, missions, and visons along with 3) the ethical conduct of research or programs within the hospital and finally 4) responsibility to develop and manage an ethics program by facilitating ethics consultations and teaching of medical staff.[1]

However, the main goal of clinical ethics is to minimize harm, and maximize benefit, manage clinical conflict and maximize resolutions, institutionalize missions of the organization and policy development, assisting medical personnel with current and future ethical problems, and continue to work on the structure of the clinical ethics service model for quality

improvement in patient care.[2] Ethics consultations improve the communication, documentation, and overall quality of care for medical teams and patients.   These consultation services are a preventative intervention in which a team or consultant analyzes the conflicting data, communicates the possible outcomes, strategizes with the medical team and or patient, develops a plan or intervention, and implements quality care into action. Ethics consultants should ensure that the decision making process is inclusive with all members of the clinical team in order to provide consistent current and future care of the patients.[3]

A clinical ethics consultants' role in the healthcare field is to develop and maintain the values of the institution by interpreting their mission along with the patient's wishes and goals in order to create an environment that constitutes quality driven care. These consults result from ethical conflicts that are derived from diverging views of how patient care should be conducted. New age medicine is not linear, and ethics consultant's roles are to detect the conflict at hand. Consultations for clinical ethicists are usually requested for multiple reasons, but mainly consist of matters of withholding or withdrawing treatment, surrogate decision making concerns, autonomy issues, end of life care, cultural or religious issues regarding care and treatment, professional responsibilities, and resolutions of ethical conflict.[4]

After resolving the conflict at hand, most ethics consultants can debrief staff and help them cope with the issue at hand. Medicine is a science to a certain extent, but now that patient values are at the forefront of care, ethics is entwining itself and weaving its way through the grey area of new age medicine. These consultants are trained individuals who can dissect and manage ethical conflicts in order to drive quality care and create ethics knowledge to medical staff for future situations. These consultants are able to dissect these problems because of their vast knowledge of American law, medicine, biology, and of course ethics and bioethics principle with

core value framework.[5] An ethics consultant's role is based upon the ethical framework, theory, and standardized practices of ethics. The ethics consultation service should have some certain criteria in order to consult clinical staff, patients, or organizations on ethical recommendations for patient care. An ethics consultant would process the request of the consult, review the chart information, talk with the patient and or clinical teams, and write recommendations based upon the ethical framework provided by standardized care by ethical expertise in the field.[6]

Most medical staff do not see the pertinent knowledge of ethics to patient care. Once certain ethical theory is ascertained by medical staff, then they too will be able to acquire new skills and knowledge that can be applied to everyday care of their patients.[7] The ethics consultant will be able to participate in the multi-disciplinary care team that will help determine the wishes and values of the patient to properly direct their future in medical care. By allowing the ethics consultant into the clinical team setting, they will be able to help identify the ethical practice, decision making skills, core competencies, and ethical knowledge to embrace all aspects of ethical practice to ensure the most valuable care for patients.[8]

Regardless of the consultation service, whether team, committee, or individual, the American Society of Bioethics and Humanities, ASBH, core competencies for healthcare ethics consultations must be represented throughout the consultation.[9] The consultant is the key mediator that embraces the core competencies in order to facilitate proper quality of care to the patient and the medical staff in conflicting situations. It is best that the consultant analyze the problem, process the situation, and run an effective ethics consultation service.[10]

The team process or group process incorporates the expertise of all specialties relevant and necessary to the clinical case whom have knowledge of the relevant information.[11] This route of clinical ethics consultation provides specialized knowledge at the immediate

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intervention of the ethics consultation. This involved care informs the whole team of detailed information rather than charting, writing, or verbally providing disconnected information throughout the team. It is important for everyone involved in the healthcare team including the patient and family to use their resources to carefully consider the ethical concerns to form feasible options for the future.[12]

The purpose of the ethics committee is to improve transitional public relations, education, development of policy and guidelines, or consultation services to suggest bureaucratic decisions to resolve complex clinical ethical dilemmas.[13] The committee is built with individual specialties that could include: legal, social work, case management, physicians, nursing, civilians, and non-clinical administrators. This work ethic of a committee provides deliberation of ethical issues in a forum to include all conceptual ideas that could permit possible ethical conclusions based upon a specialized body of knowledge. By having an ethics committee, the hospital can integrate the community and clinical practice among the representing experts to advocate a strong role for clinical ethics consultations.[14]

The individual ethics consultant has the task of merging together ethical issues that range from social, legal, theological, economic, and political which need to be separated and developed into what is morally relevant to the clinical ethics case.[15] This individual ethics consultation model allows for the ethics consultant to be more one on one with the patient which encourages a stronger trusting relationship between the clinical side and the patient advocate side. The consultant has the opportunity to know the patient as a person and not just as a medical anomaly and can therefore interpret better the patient's pertinent values and attitudes.[16]

I.a.ii. Implementation of Ethical Theory:

All interpretations of clinical ethics consultation services previously discussed are able to be implemented in any form throughout a healthcare system. However, accepting a range of

consultation services in a hospital may be even more appropriate because every case is exceptionally different on its own. Ethics consultation services focus on providing a service that addresses any ethics issues that arise in a particular case by team based approach, individual or community group depending on the ethical dilemma at the time of the consultation.[17]

Ethical theory transitioned into practice requires a certain didactic training that emanates from a non-linear viewpoint. Ethics is obtuse, there is no simple linear line leading to the answer. It bends, and weaves differing theories into a conveyed moral practice of ethical solutions to resolve conflicting problems. Participants in this practice frame their moral obligations to the patient by assessing the various standards and policies of the organization itself, and globally to deliberate the moral considerations that should be viewed to reject, correct, or expand the ethical obligation in medical practice.[18]

An ethics consultation format for most scenarios have a typical procedure on how to move about the consultation. Once the request is verified, a consultant should gather information from all parties involved in the situation to best understand the patient's values and wishes, and the medical staff's opinion of the best scenarios for care.[19] The job of the consultant is to best analyze the situation to come to the conclusion through multiple conversations with patient and medical staff to resolve the ethical problems. More often than not, if all parties are included in the individuals' care, and are able to express their views about the situation, it is easier to come to an ethical conclusion in care based upon all specialties involved in the individualized situation.[20] After assembling the proper team and evaluating the situation, this centralized care unit can work through the case to facilitate the proper ethical conclusion.[21]

Shared decision making includes the primary physician team, family, patient (if competent), and any other specialties involved in the patient's care. Miscommunication may be

the reason why the patient and or family are resisting in certain measures of care. A family meeting allows for decisions to be made with no misconceptions, misunderstandings, or mistreatment. Each person is able to play a critical role in the treatment process of the patient. Shared decision making is a back and forth process that may take more than one meeting with the patient and or family to correct misunderstandings making it easier to understand and to accept recommendations so as to share in the continuum of care.[22]

After a team meeting has been completed, the discussion and plan should be documented in the patient's chart ensuring that the recommendations are clear so that misunderstandings are avoided in future care.[23] Documentation is crucial so that it states the patients' wishes, and goals of care so that if at any time a patient becomes incapacitated, the medical team and ethics can be their advocate. Once all information is gathered, and a conclusion has been made, the consultant should follow up with the case and learn what was done, assess how the service was perceived, and ask for feedback.[24]

Implementation of ethical theory will help back the ethical suggestions and progressive treatment options for patients and their goaled care. The conflict of ethical theory arises mainly between the autonomy right of the patient versus the beneficent right of the physician and medical teams.[25] The patient has their own personal value and goals of their medical care, and physicians are supposed to do what is best for the patient and sometimes these goals are diverging. These views may be diverging but it is the goal to pull ethical theory to align both the rights of the patient and rights of the physician to produce a lasting pathway of morally righteous healthcare. Ethics is based upon the normative theory of right action by depicting what is morally right and what is morally wrong and this mantra should manifest itself throughout healthcare.[26]

Ethical theory, moral competencies, and patient rights are no good if clinical personnel cannot implement them into practice. There needs to be an ethical obligation that ethics consultants can provide experiential knowledge and ethical theory to better promote ethics in a clinical setting. Utilizing mechanisms embedded within an organization will further craft policies, and recommendations of bioethical issues amongst clinical providers and ethics committees.[27] An Ethicist is able to teach the moral competencies, knowledge, and theory to professionals so that they themselves can deal with ethical dilemmas in real life clinical situations.[28]

The aims of an ethics consultation is to envelop some of the core competencies such as: listening well, recognizing the barriers of communication gaps, representing views of all parties involved, demonstrating sensitivity to the medical team and patient, and negotiating a distinguished well documented approach to clinical ethics in medicine.[29] Implementing these areas of expertise in a clinical ethics consultation bridges the communication gap between patient and physician. The implementation of any type of ethics consultations will address the uncertainty or conflicts that typically emerge pertaining to patient care.[30]

The implementation of ethics at an organizational level should be the development of organizational responsibilities with respect to moral obligations of employees to foster a climate that exudes a respectful environment and moral commitments to their patients.[31] This theory is sought after for the mere fact that medical personnel employed in a healthcare institution should foster the goals of the organization in their practice of medicine. Developing ethical theory into practice will require a cultural shift in most medical staff to learn and better understand the changing cultural norms in medicine to support targeted goals of the patient care, and moving beyond the narrow minded clinical focus of care.[32]

<u>I.a.iii. Documentation of Ethics Consultation:</u>

Typically, hospital charting contains clinical information about the patient and the clinical events and essential information pertaining to their hospital stay that is critical for communication and diagnosis among the clinical teams.[33] This information is easily shared through most electronic medical record systems. Teams can then conduct face to face meetings, or phone calls by reading the charted data that is electronically signed by all involved clinical teams. The information that documentation provides is crucial for quality care, in that the end all providers that are participating in the patients care have been informed of the decisions made prior to implementation and can then complete their own documentation based upon the known information from previous notes.[34]

During an ethics consultation, the consultant will need to find important information provided by multiple disciplinary teams, and without proper documentation the consultation provided is not conducive to quality continuum care. First, the consultant should clarify the condition of the request for ethics specialty, then gather the information from all other specialty teams, and then describe the ethics perception of the problem and explain the recommendations to move forward by documentation in the patient's chart.[35] Discussions of goals of care, legal ethics, competency of a patient, cultural or spiritual issues, advance directives, or conflicting viewpoints should all be documented with complex cases so all medical teams involved are informed of pertinent information to manage the case at hand.[36]

There are three standard documentation approaches to ethics consultations. CASES Approach stands for: clarify, assemble, synthesize, explain, and support.[37] This approach is fairly straightforward and has the most specific conjugated steps to take on a detailed ethics consultation. The first step in this approach is to clarify the consultation. This means that the ethics consultant needs to first ask the team requesting the consult, what the consultation is

actually for. Next, the consultant should assemble all pertinent information that is necessary to analyze the case from an ethical perspective. Synthesize means to gather all relevant teams involved in the patient's case to communicate effectively all possible avenues of care this patient may or may not participate in. Then, a care plan can be administered by every team involved in the coordination of care. Lastly, support is dealt with following up with the patient or team if the case needs any additional conflict management. This can also mean debriefing staff after the consult if there are any questions or concerns about the previous patient case.

The Four Topics Method or 'Quadrants Method' consists of four broad topics: medical indications, patient preferences, quality of life, and contextual features.[38] Medical indications is the first quadrant which deals with the medical logistics of the case and the probabilities and options for the patient. The second quadrant is patient preferences which refers to the patient's wants or inclinations about their route of care that can coincide with the medical indications presented. The quality of life quadrant includes the patient's wishes, values, and wants about the rest of their life if certain medical avenues would need to be pursued. Lastly, the contextual features quadrant relays the patient and families values, language preference, interests, cultural aspects, views on treatment, or money woes. All of these aspects play a great deal in the decisions of care, even though they are not a medical stipulation they are equally important for the congruence of care.

The Process and Format Approach includes: the consultation request, documentation of the ethics consultation, and completion of the ethics consultation. This approach focuses on the documentation in the patient's chart and bridges direct contact with the patient to elicit an updated approach to ethics consultation.[39] When a team requests a consultation the consultant must find out what an ethics consultation can do to help the conflict at hand. Then they must

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have conversations with the appropriate team members involved in the patient's care in order to document the correct information in the patient's chart. The completion of the consultation will most always result in a follow up visit with the clinical team or the patient depending on the scenario. This way, the consultant has documented the recommendations and has followed up with the appropriate people in order to carry out the end of their duty to patient and medical team.

Documentation in end of life care and decision making process should be expected in all cases, but this varies within hospital systems and regions in many countries.[40] The end of life decision making process is normally not a one-time discussion which means that all conversations should be documented in the chart so that each part of the medical team understands the situation at hand. Documentation should be carefully worded and stated with care pertaining to perspectives of ethical conflict at the end of life between staff, patients, and or family members.[41]

Documentation is mandated for essential reasons such as: assessing, evaluating, and implementing care for patients in order for the quality of care to be managed between clinical care teams, and for legality issues.[42] Ethical framework and theory are able to flow between the documentation, assessment and plan of care throughout the patient's medical stay. This way ethical competencies and actions guide the plan of care and are able to give proper ethical knowledge to clinical staff through documentation in the patient's chart. Once ethical guidelines and competencies are documented in the patient's chart the value of the chart data can be used for reimbursement, performance measurement, and data.[43]

I.a.iv. Possible Costing Approaches For Ethics Consultants:

The approach to clinically coding ethics consultations for cost based analysis has yet to be done. The RVU, metrics that physicians use for payment is based upon their allotted time

spent with patient's, procedural costs, academic productivity, and or clinical workloads.[44] The documentation of an ethics consultation should include the request, the data collected, and the recommendation in order to charge over and above salary, which most departments do not do use at this time, but should be a possible development for future consultation services.[45]

However, the RVU system is flawed in the sense that it is heavily biased as to assessing the comparable worth of differentiating clinical activities and or procedures.[46] This system may not take into account the specialized knowledge and procedural responsibilities an ethics consultant provides. This system may only focus on the clinical or academic agenda and only include one cost based analysis rather than differentiating the clinical expertise of consultations just as any specialized medical practice. There may need to be a more complex system to bill and quantify ethics consultation services. Hospital cost accounting method estimates the procedure level costs by incorporating a ratio of departmental costs to charges and then applies this ratio to the individual charges for a procedure computing the estimate of billed potential.[47] Combining the RVU based ratio and the hospital cost accounting method may allow for a more detailed metric system to develop fee for service depending on the complexity of the case consultation or other ethics oriented services.

Some non-physician clinical ethicists have billed for consultation directly to the institution requesting a consultation or have billed as an initial consultation code within a healthcare organization as a physician.[48] Many consultants that work within a healthcare organization are salaried, but do not bill the patient or service requesting the consultation.[49] A third party option may be a better approach. This approach would include a fee scale for ethics consultations that use a third party such as insurance to bill for the use of the service based upon

the coded issue at hand.[50] Consultation charges could include: challenge or longevity of a case, the urgency of the consultation, policy changes, and conflict resolution.[51]

The concerning issue of compensation or fee for service for ethics consultations resides in the certification process. There is currently no certification or mandated expectations required for ethics consultants before leading consultations. There ought to be a defined body of knowledge and skills, examinations, and provide a board certification for ethics consultants to practice in the medical field.[52] The certification process needs to be defined in order to bill for consultations. Patients or clinical staff members that request a consultation should view the consultant as a board certified professional such as their physician colleagues. If their service is clinically helpful, cost effective, and valued by other providers then their service should be provided as a benefit or specialty to patients and hospital systems.[53]

II.B. Preventative Healthcare Ethics:

Preventative ethics in medicine is becoming an important concept to achieve. It allows for higher standards of care in the forefront of their medical endeavor so that their readmission rate is low and their standard of care is set at a higher level. The culture of the organization also plays a role in preventative ethics. If the obligations of the organization are the same obligations of their employed medical staff the culture of the organization will thrive for a stronger quality of care. Calculating what an ethics consultation can do for a health system can easily be documented by the admission and discharge stages of the patients. Calculations can be done to show the preventative services, quality care, non-readmission rates, early consultation process, early discharges, and integrated care that encourages preventative measures to exist in medicine. This also introduces system wide cost reduction that benefits both the hospital system and

patients with shortened lengths of stay. By using preventative ethics the organization can promote a higher quality of care.

II.b.i. Preventative Ethics:

Preventative ethics is the pure goal of addressing ethical concerns to improve quality by identifying, prioritizing, and adhering to quality gaps in patient care. The approach of preventative ethics is a multi-system level approach. Preventative ethics is an embedded and integrated delicate system to promote if the clinical staff, administration, management, and the overall culture of the organization is at odds. Most organizations make the mistake of being in a reactive mode. This means that the organization spends too much time on decisions and actions of fixing the conflict or problem at hand instead of focusing on why the conflict arose through the gaps in quality of systems, processes and culture of the organization.[54]

By focusing on the crisis at hand instead of focusing on corrective action to improve the system to address issues that include: patient, family, unit, and system, which if reoccurring, then also triggers repetitive ethical conflicts. This lack of communication and / or team consensus, unclear discussions leading patients false hope, and ineffective hand off of report information promotes inconsistent and ineffectively established hierarchical procedures.[55] Staying in a reactive mode does not fix the problems that are consistent and reoccurring. It is better to identify the reoccurring issues and to refocus the organization to improve the quality by creating a comprehensive approach to coordinate care. The organization and its' employees will need a quality improvement mindset to tackle the components of ethics quality to develop new policies and standards within the healthcare organization to exude a preventative ethics approach to patient care.[56]

Preventative ethics is carried out by the implementation of academic nomenclature to improve the status of perceiving the need for structure, process, attitudes, and a process of medical education to improve medical care.[57] The role of preventative ethics will not be economically based; it must rather be designed to prevent one from further harm or further possibility of increased chronic healthcare conditions. Preventative ethics provides healthcare systems continuous quality improvements based upon the system's performance, team compositions, proficiencies, and identification of ethical issues throughout the system whole.[58]

At the organizational level, preventative ethics can identify the institutional gaps to address the ethical quality gaps in care and process solutions to improve practice consistently.[59] This way, risks and gaps in care are identified and addressed before the problem reaches chronic levels and is controlled in the interim. A measure to calculate preventative services positive effect is to combine the years of life gained with the improvements in health which relates to the quality of care in the system .[60]

Reallocation of resources to physicians and clinical staff members is pertinent to the survival of preventative care medicine.[61] By requiring staff surveys, quality feedback can achieve and promote a quality improvement plan by facilitating preventative ethics in medicine. Nursing staff can play a critical role within the preventive ethics improvement model because their professional knowledge of unit function, identifying unit based patient conflicts, and unit resources will be key to implementing a preventative ethics approach per patient unit based population.[62] By implementing a preventative approach such as: appropriate physician consults, coordination of care, effectiveness of treatment plans, patient feedback, and cost effectiveness, all these approaches will improve the healthcare delivery system.[63]

The resistance to change and the lack of capacity for many to adapt easily is worrisome for healthcare organizations. Preventative and integrated ethics within a healthcare organization can provides a high degree of quality of ethical care. Without quality and ethics, then the care of patients suffers greatly and is not of quality or of any healthcare standard, so innately these two concepts go hand in hand.[64] The healthcare institution as a whole was created to care for individuals in their time of need. These patients expect that by walking through hospital doors they are going to receive standardized medical care that is coordinated, comprehensive, and of quality. Integrated preventative ethics refocuses a disorganized healthcare system into a proactive and collaborative organization that uses the aspects of ethics and the company's mission statement of valued patient care as a driving factor to ultimately increase ethics quality within organizational systems.[65]

I.b.ii. Embodying an Ethical Organizational Culture:

The organization's culture plays the role in preventative ethics based upon the moral obligations and values that the institution upholds for everyday care. The commitments of the clinical staff foster the act of "what should be done" for the quality healthcare based upon the moral convictions of the organization and the values fostered within the systems.[66] The relationship between preventative medicine and the healthcare organization will be solely dominated by the moral stand of the healthcare workforce and the individual determination of moral duty to their patients. The dominant valued culture between staff and its organization can thrive based upon embedding values, beliefs, and ethical norms for a more cultivated quality care.[67]

Culture justifies action because the culture will embody and reflect the implemented structure of the organization to achieve quality, cohesiveness, organizational identity, innovativeness, and collegiality.[68] The action taken by staff members are conducive to the

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cultural environment someone immerses themselves into. If this environment is hostile then actions may be of anger, distrust, or distain, but if the environment is supportive then actions would thrive off of the positive energy and be more reflective of the organization's identity. Most organizations will promote either a group culture that is based upon norms and values of the organization; a developmental culture focused on change and innovations; or a hierarchical culture that focuses on the control and stability of the organization, but the key is to find which method best drives the organization's values across their system.[69]

Perceptions of hospital environments are seen through quality patient care. However, job satisfaction plays high importance. By adhering to the staff's work needs, allowing for authority in decision making amongst nurses, promoting and reinforcing mutual trust and respect, are not enough unless they feel a sense of equality / importance between all medial staff.[70] The job satisfaction amongst nursing and other medical staff members are key to the quality of care patients receive. If the staff are immersed in a culture that is not conducive to essential ethical standards, respect for one another, or just decent common curtesy, the organization fails because the staff ultimately produces the desired level of quality patient care. Building and supporting a cultural humility will assist in developing self-reflection of personal behaviors, encourage educational growth experiences, and entice engagement in the process of mutually respectful dynamic partnerships.[71]

The symbolic aspect of quality patient care has been diminished as professional attributes are seen as fundamental skills rather than an interactive skill sets.[72] The tactics now developed in medical school and residency programs are focused upon medical knowledge, but fail terribly at meeting interactive skills when with other staff members and patients. In an age of increasing technological advances, mankind has become desensitized to human interaction. Quality care

thrives off of human interaction. Rather than diminishing patient and other medical team views, use them as an alliance to affect change and develop a cultural therapeutic alliance that focuses back to the value laden care patients deserve.[73]

Reinventing the perspective of professional standards, patient-doctor relationships, patient safety, staff trust, and outlining responsibilities are key to enhancing the practice of the organization.[74] The key stakeholders of these medical organizations do not speak of how fantastic their care was, or their trust in the organization, or the missions of the organization fledged across all aspects of care, but people who enter the doors of most medical institutions speak do speak of these and of the disorganization, the lack of respect, communication, and ultimately the low quality of care because these factors do not exist. The technical curriculum level achieved, no matter how outstanding the level of knowledge, does not replace or suffice where there exists a lack of : sensitivity, communication skills, virtues, and compassion thus isolating physicians as single players rather than a part of an embodied value encompassed team of experts.[75]

Clinical ethics consultants can implement the value ethos of the healthcare institution and educate medical personnel to embody the value system that best facilitates sensitive clinical care.[76] Clinical ethicists can engage organizational culture, education, and values to induce collaborative patient care. A radical cry for reinventing professionalism in the medical field is prominent and visionary leaders, such as clinical ethicists that can support the process of change and will bridge the gap of medical performance and distrust in the medical arena, promote competence of organizational values and enhancement of core values.[77]

Studies have shown that a good place to work correlates with patients receiving excellent care.[78] Organizational culture drives attitudes, values, and goals in patient and staff interactions.

Organizational change and educational curriculum needs to occur in order to drive listening and responding skills, trust and respect to better serve the patient's best interests.[79] The discontent of patients and families alongside medical staff based on their organization's cultural environment is not acceptable anymore. There is a united cry for medical care to reach the compassionate grace it once was. The medical field has lost its way, but redefining quality care patients so deserve will again change the face of medicine. Redefining clinical staff and authority to oneself and others will create an atmosphere disciplined to work together to achieve a beneficial environment for all.[80]

II.b.iii. Calculations of Before and After the Ethics Consultation in the Healthcare Setting:

Interventions of palliative services or ethics consultations have shown reductions in prolonged dying processes, and lengths of stays in the intensive care units.[81] These teams specialize in patient conflicts about goals of care, patient values, and end of life decisions. Their expertise usually thrives off of exquisite patient dialogue, connecting team evaluations together, and culminating with a team evaluated plan of action. Sometimes, all the approach needed to dictate faster quality care is proactive clinical communication and sound ethical dialogue.[82]

End of life decision making is one of the most expensive and time consuming decisions for patients, families, and medical staff. The number of deaths in an intensive care unit after the withdrawal of life support are now about ninety percent of the patient population that have passed after deciding to limit life sustaining therapies.[83] One of the main questions at the end of life circles around tracheostomy and peg tube placements that will help with sustaining life, but the question of families and physicians is to what end.[84] These two procedures could extend life and prolong hospital stays in intensive care units. The movement of clinical ethics consultants and physicians have been recognized as providing a dignified and tolerable death among

critically ill patients and making it an obligation to treat symptom relief as well as emotional and spiritual concerns.[85]

Families and or staff members may not be able to let go of a patient for a number of reasons. This conflict in emotions is one of the driving factors of prolonging life sustaining therapies or treatments which drive costs for both the family and hospital. Identifying a person of authority that is willing to listen and share decision making to collaborate on an interdisciplinary team to set daily goals that can reach agreed upon care could improve the quality of care and facilitate a stronger coordination of care.[86]

One study was done showing the triggers of a consultation, which resulted in emotional triggers, assistance with communication, responding to conflicts of emotionally charged situations or conflict crisis resolutions, and dealing with family members.[87] Clinical ethicists can proactively decompress emotionally charged situations and resolve conflicts at hand if consulted in a timely manner. By using a proactive method of consulting an ethics team early on in the care process, they can orient the intervention by collaboratively implementing a care plan.[88]

Another study showed the difference between a proactive ethics consulting group, and a group which obtained no help from ethics. Members of the proactive group spent six days less than the non-ethics group, the patients that died because of proactive consultation services per patient wishes were out of the intensive care unit by thirteen days shorter than the non-ethics group, the active group had six percent lower charges and thirteen percent lower costs from the patients who died than the non-active group, and lastly the active group had significantly higher communication scores than the non-active group.[89] Proactive ethics consultation services have increased communication, decreased costs to patients and the hospital system, and carried out patient wishes more productively at the end of life. Ethicists can adapt to the conflict at hand,

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communicate the values of the patient, document the plan of action, and educate the medical team about the ethical pieces of the mediation conflict. Physicians most likely call upon clinical ethics consultants to mediate the conflict at hand at an early stage so that the situation is diffused early, and the ethical analysis educates the medical team for like situations in the future.[90]

A preventative ethics approach of having ethics consultants on surgical rounds to intercept possible conflicts that may arise such as the knowledge / law of enforcing "do not resuscitate orders" so they are observed as requested and so they are there to assist family members and patients with this choice to an excepted conclusion without extending length of stay. After loss is observed, the result is a benefit to the medical teams, hospital and ultimately the family by this reduced stress / extended grief and length of stay as was desired.[91] The ethics team can reliably prevent most conflicts if they are actively involved in the beginning of the care such as goals of care conversations before admission or upon lucidity of a paradoxical situation. If involved early on, most ethics consultants can provide ethical analysis of the situation in order to give advice for future care regarding treatment decisions for critically or terminally ill patients. Fifty-five percent of physicians in one study requested and recommended ethics consultations for management of care.[92] These physician's requests for medical ethics actively engaged a faster and more equipped quality care resulting in a strong healthcare system.

II.b.iv. System Wide Calculation of Cost Reduction:

In the United States alone, the intensive care units account for twenty percent of inpatient costs that may be reduced by an ethics consultation of a trained, and experienced medical ethicist.[93] The cost for caring for patients in the intensive care units now accounts for a total U.S. healthcare cost of thirty-eight percent.[94] The relative information of cost reduction, preventative ethics, and surveys conveyed will better access staff needs for ethics consultation to be relayed to clinical staff in order to have a quality productive healthcare organization that

benefits both the patients and the hospital system. An ethics consultation service can help resolve the ethical conflicts, produce preventative services, and help resolve conflicts that result in less undesirable days in the hospital system.[95]

There are four economic costs associated with ethical conflict in patient care: operational costs, legal costs, marketing costs, and public relation costs.[96] These costs pay a toll on any healthcare system. The estimated costs of an ethics consultation practice for a small hospital per one study estimated one hundred and fifty thousand dollars a year that would acquire one full time consultant and assistant with benefits including overhead and office space.[97] This cost incurred by the hospital system is minimal compared to the costs of an intensive care unit patient per day due to ethical conflict at the end of life. By implementing advanced care planning from clinical ethics consultants they would be able to address frequency admission issues, impact of costs on reoccurring ethics issues, and improve quality patient centered care at a fraction of the cost.[98]

One ethics consultation service group study observed that forty intensive care beds had a cost savings of approximately over a hundred and fifty thousand dollars a year due to ethics consultation services and the study showed consultations to be most effective with patients having had a greater stay with more than ten days.[99] This shows that the cost of one ethics consultant is equal to forty ICU beds in a small hospital dealing with ethical conflict and in turn reducing lengths of stays. In turn, a large hospital system would benefit from ethics consultation services on a regular basis that is integrated into their collaborative care teams to provide a more effective end of life care plan both reducing hospital costs and patient fees.

Ethical conflicts at the end of life pertaining to futile care, inappropriate treatment, ineffective treatment, or surrogate communication and professional conflicts are some of the

most complex emotionally charged situations that result in promoting beneficial, and timely patient centered care.[100] The economic cost savings in death circle around the dignity and respect of death, not in the notion of a faster discharge. The discharge of a patient may in turn be quicker, however, without the understanding of the patient's values and beliefs, ethical conflict will keep arising. Closely managing the patient's cultural beliefs, pain management, emotional distress, and respect at the end of life is among the important obligations of the ethics consultant to refocus the shift in goals to humanistic skills rather than the technical desensitized mindset healthcare professionals may unknowingly become.[101] Without the value and quality improvement in end of life experiences and death, the hospital system will cease to acknowledge economic cost savings by disregarding the improvement of quality at the end of life.[102]

The last weeks of life are the most extensive costs to a healthcare system, and can be reduced by actively limiting wasteful interventions and enacting advance directives to achieve curtailed end of life costs both translating to good ethics and quality care.[103] Ethics consultations can ensure advance directives are being documented and carried out throughout the medical system. They can also alleviate the ethical contradictions that usually reveal themselves during end of life care, and provide ethical framework and or theory to ease the agitation of patients, families, and medical staff. This will in turn reflect the cost reduction at the end of life with faster documentation and goals of care. Consults will lead to a reduction in inappropriate or prolonged treatment, unwanted treatments, or futile treatments.

Cost reduction during patient stay during end of life care can usually be seen aligned with palliative care. Ethics teams usually work closely with palliative care at the end of life. This service provides pain management and advance directive issues to be addressed and communicated appropriately. Palliative care also work alongside ethics which is seen as a

supportive care service. This service when consulted has cut costs of patient stays on an average of $490 a day over an entire admission resulting in discharging patients with savings in the thousands.[104] Working alongside ethics services, these cost reductions are due to the promotion of continuously improved communication and personnel who are continuously diligent in striving for the maximum synergy between medical teams including palliative medicine thus resulting in optimum patient care. The economics of dying coincides with ethics consultation services that resolve conflict by providing timely and reliable information, the understanding of the disease or treatment options, all pathways of care, respecting cultural values, and supporting other resource allocations for quality care.[105]

II. ASBH Core Competencies for Ethics Consultation:

This section will explain in more detail the core competencies of ASBH, ASBH competent staff and involvement of ethics consultants, surveys to staff on competency of ethics, and conflict management capabilities.

II.A. ASBH core competencies:

In this section, the core competencies for ASBH involve particular competencies for an ethics consultant to be an expert and recommend particular ethical suggestions to proceed in clinical care. These recommendations are based upon proper knowledge of ethical literature, framework, standardized care, ethical duties, responsibilities, and actions based upon ethical theories and practices in ethics. This chapter will shadow the need for standardized pediatric healthcare ethics consultations based upon ASBH core competencies. There is a need for pediatric ethics consultations. Clinical staff do not have enough pertinent ethics training to advise or council patients and or families when an ethical conflict arises. By directing staff to take surveys on ethics competencies, the system will be able to better implement a devised plan

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to navigate ethical procedures within their system of care and further design, focus and provide staff training based on what is needed from this information. Beyond ethics competency, conflict management capabilities are extremely important for everyday activity. Bedside nursing, nursing aides, nursing management, physicians, and other clinical staff members, all should be trained in conflict management so that the intense conflicts that arise within the care of the patient can be addressed in a timely manner. Ethics consultation services can provide competency training and conflict management training to further quality of care in healthcare. In order to have involvement for all parties to determine the best care possible for the child patient, clinical staff members need to be educated and competent enough in ethics to recognize and identify ethical conflicts that may be stirring. With a competent staff, quality based care can be ensured.

II.a.i. The core competencies of ASBH:

To assertively assess a clinical case in which an ethical conflict presents itself, the ethics consultant must have the ethical assessment and analysis skills to competently analyze the ethical implications at hand. These core skills would be to gather all relevant information, distinguish which details are ethical and which are more relevant for another clinical team, articulate ethical concerns, identify beliefs or values of the patient, clarify ethical concepts, codes, or standards to evaluate all possible outcomes that the situation could ethically be permissible based on patient's goals of care.[106] Then the ethics consultant can make recommendations consistent with the ethics framework and can resolve the conflict at hand by discussing among the ethically acceptable options.[107]

The core competencies are not only one of the most important ethical approaches and foundations to ethics consultations, but also provide knowledge of ethical guidance to properly train newly developed ethics consultants. These consultants should have knowledge of

consequentialist, non-consequentialist, utilitarian, Kantian, Communitarian, Deontological, nature of ethics, and human right approaches in order to apply them to ethical or theoretical foundations in supplying validity to their recommendation.[108]

The core competencies set a level of competence in ethics that requires an ethicist to be able to communicate, negotiate, recognize, demonstrate, and distinguish quality improvement skills in order to circumnavigate constrained behaviors in ethics consultations.[109] Being able to use core competencies and skills allows for an easier consultation based upon formal ethics training and ASBH guidelines. ASBH core competencies have set the standards for ethics consultations, and have evaluated the methods and tools needed for a quality ethics consultation efficiency and efficacy.[110]

The ethics consultant should develop their role as a specialist in the field of ethics. Just like any healthcare specialty, the ethicist has a plan of action to achieve the highest possible ethically appropriate care for his or her patients. The healthcare ethics consultants must be able to gather pertinent information to navigate the medical diagnosis, in order to evaluate, interpret, analyze, foster communication, and promote the recommendations of the ethically acceptable plan of action agreed upon by all parties involved.[111]

The aims of an ethics consultation is to envelop some of the core competencies such as: listening well, recognizing the barriers of communication gaps, representing views of all parties involved, demonstrating sensitivity to the medical team and patient, and negotiating a distinguished well documented approach to clinical ethics in medicine.[112] Implementing these areas of expertise in a clinical ethics consultation bridges the communication gap between patient and physician. The implementation of any type of ethics consultations will address the uncertainty or conflicts that typically emerge pertaining to patient care.[113]

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Since the field of clinical ethics is just starting to become apparent in the healthcare industry, new ethics consultants rely on their advisors and the training from veteran ethicists.[114] It is important to note that clinical rotations, internships, fellowships, and residencies in bioethics are equivocal to that of medical schools or physician residency programs in which the attending physician or attending ethicist teaches the resident how to apply knowledge to real life clinical experiences. It is always a good idea to shadow and observe how a seasoned clinical ethics consultant goes about an ethics consultation.[115]

II.a.ii. ASBH Competent Staff and Involvement of Ethics Consultants:

This basis of care approach and best interests' standards only thrive if staff are competent in ethics. This way medical ethicists can give an ethical analysis and document the ethical contraindications of a clinical case so staff members in turn can learn about ethical conflicts, dilemmas, and conflicting situations. The professional clinical staff should have certain specialized criteria that should be required in order to demonstrate continuing competencies and educational credits.[116] A proactive approach to ethical conflict for clinical staff would be to shadow or witness ethical cases and learn about the development of ethical issues so they are further aware and able to appropriately act on the ethically grounded protocols that have been set forth by accredited programs.[117]

The ethics consultation service within the system identifies and resolves ethical dilemmas, respectfully recommends routes of care to maximize benefits, reduces harms for the patient, and tries to prevent poor outcomes before they occur.[118] Not only do ethics consultants partake in these interventions of patient care, but they can teach clinical staff members to view a case differently. Clinical ethics conflicts take a specialized skillset to recognize. Beyond recognition, clinical staff members need to have the education and competencies to encourage careful delivery of care and appropriate interventions for the best interests of the patient.[119]

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The team approach or learning approach implies that the involvement of all staff members on the patient's case, the family and the patient encompass the ideal care because all information given presents a collective competent staff executing the maximum benefit for the patient.[120] Competent staff is driven from ethics education and an open dialogue between all clinical teams to best serve the patient's interests in an optimal time frame to prevent possible ethical dilemmas or communication errors.[121]

Competent staff in ethics can greater support cost reduction, quality improvement, and ethical identification prevention. Cost reduction usually correlates with the length of stay and how long patients are in the intensive care units that are more expensive than regular medical floors. If medical staff members can identify foreseeable ethical problems before they arise, cost reduction in the intensive care units could be reduced. The reduction of average costs per patient in one study is about ten thousand dollars per patient when ethics intervention is utilized. This indicates costs can be reduced because ultimately a reduction in length of stay by cooperative decision making conversations as a team effort, and by being respectful and supportive of family and patient values alongside institutional ethics standards results in positive outcomes for all when this is the foundation supporting patient care.[122]

Proactive ethics consultations are provided by competent staff initiating the conversations and dialogues with the patient and family and heighten their attention to the ethical conflict, communication errors, or challenging emotional dynamics that may arise during critical care of a patient.[123] When staff proactively identify issues that may worsen their patient's stay by making harmful decisions that are against patient wishes, or noticing when one is suggesting inappropriate treatments that physiologically cannot extend a patient's life, and essentially are costing patients' their values or wishes at the end of life, benefits all concerned if these notions

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are eliminated early in the process. If these wishes or values are not documented in advance

directives, living will, or a documented healthcare agent then the patient forgoes an easier

passage to death. Competent staff in ethics creates ease in end of life issues. Statistics show that

by providing advance directives in terminally ill patients at the beginning of their medical

journey, the clinical teams reduce the patient's cost at the end of life by twenty-five to forty

percent that relieves the family and patient burden of choice in an undesirable moment of

continued life support or comfort measures.[124]

Providing ethics training and staff education upholds the values and patient wishes at the

end of life. Clinical staff decisions can center on the patient as a whole and understand their life

goals in order to implement an ethics plan for their medical stay. One study showed that by the

end of a proactive ethics consultation, all team members thought that the consultation was

needed, and the informed decision made by all parties was with the basis of the patient's

convictions at the end of life.[125] Core competencies such as the four main principles of bioethics

that include: autonomy, beneficence, non-maleficence, and justice are all embedded into the

consultation process. It should be noted that because all of these terms refer to living changing

methodologies and actions, we should always remember that this is a continuous process and our

theories of how to perform our ethical duties should always be changing and evolving with the

focus on that of the patient and his or her voice. It is up to the physicians, nurses, and other

medical staff to be uniquely trained in both clinical medicine and medical ethics to properly

support their patients and to take on a proactive all-inclusive approach to caring for patients in

this century on and onward.[126]

II.a.iii. Surveys to Staff on Competency of Ethics:

Staff competency of ethics defaults to the background of medical practice. Most people

can feel a right or wrong thing to do in a situation, but to act on it and to back up their defense

with ethical analysis is a different arena of care. Medical staff should have a greater understanding of ethics competencies. It will increase their knowledge of new age medical practice and set a higher bar for quality care for their patients. Physicians and nurses should have ethics competency training in school before clinical practice, and then should have continuing education in practice. These will help patient's overall care that is defined by their own wishes and goals in their medical treatment.

Ethics education is lacking in physicians graduating from medical schools and extends into their residency programs. This education is necessary to be a physician because without ethics, physicians become more and more desensitized to their patient's care, and become more concerned by only medical necessities rather than a patient's overall well-being. Care in today's medical field means far more than diagnosing the medical illness and discharging a patient. Now, medical care involves quality of life, beneficence, listening, patient values, and patient goals or wishes. This care is a team effort, and it first starts by educating the physician in medical school and followed by reinforced training alongside their residency programs.

The ethics education of nursing should promote moral reasoning skills, ethical knowledge, ethical principles, code of ethics, moral sensitivity, and conflict management.[127] With this education, nurses will be able to identify the ethical issue and be able to properly address the situation or call upon an ethics consultant to help with the conflict at hand. The problem is not always identifying the issue. The problem lies with addressing the issue at hand. For example, most nurses are able to identify the right thing to do, but it is the requirement for assertiveness of presenting correctly the issue at hand to the physician or other staff members so the situation can be resolved and the conflict eliminated which becomes most distressful to cope with when trying to ignore their own personal morals.[128]

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Ethics rounds include a consultant on staff that would participate in medical rounds with physicians, nurses and other care providers on the floors with the objective to integrate stronger communication amongst teams, correlate treatment plans, and quality ethical care. These rounds will discuss the patient's medical needs as well as: spirituality or pastoral care, cultural barriers, legal risks, conflicts, or discussions on end of life care.[129] A recent study showed that ninety five percent of physicians think that having an ethics consultation service available is an important and extremely useful.[130] Many medical students as well as residents would like to see more ethics training earlier on so that they have a grasp of when ethical conflicts arise arising in their patient's medical care because they better know how to identify them and can at an earlier stage so they might potentially be able to resolve issues during medical rounds of patient care.[131]

One of the ways ethics consultations thrive or are so successful is when staff realize that there is an ethical conflict at hand and they need a specialized team to help address the issues at hand. The clinical ethics consultant aims to efficiently analyze the ethical problems and systemically with the clinical team determine a grounded ethical treatment plan for the individual patient at hand.[132] The ethics consultant does not do this task alone. The help of the clinical team and all representatives on the case make a reasonable consensus achievable at a quality infused rate. The initial competency starts with the identification of an ethical dilemma or foreseeable issue.

Ethics contributes to a positive working environment that institutes the integrity of the organization and medical practice as a whole by identifying the core values and competencies of ethics and applies them to medical practice.[133] When staff immerse themselves in the ethics of medical complications they are able to devise a plan of care that best suits the patient's and or families' needs. A study was done over the course of five years on the impact of ethics

consultations with pediatric patients and their families. The clinical team reached consensus of ninety-eight percent, and families with pediatric patients reached a consensus of ninety percent when there was a contribution of a clinical ethics specialist present for clinically complex cases during determination of treatment plans.[134]

One study showed about eighty-seven percent of nurses and physicians agreed that ethics consultations were helpful and that ninety percent of them would seek the consultation service again.[135] Physicians and nursing notice that their communication choices or routes of discussion of sensitive topics could be approached differently. Differentiating attitudes, fears, cultural values, social support, important goals, and understanding the values of the family or patient is a pertinent aspect in the analysis of achieving a successful empathetic consensus of support during difficult decisions.[136]

A way that can involve all staff members is teaching ethics at the bedside where personnel can experience the ethical issues and solutions in clinical care.[137] The whole team that could range from housekeeping to nurses to physicians can be involved in the educational experience. "Education and collaboration" are a clear connection with medical ethics in patient care and are directly connected.[138] If medical ethics is continued to be seen as education at the bedside then the hospital unit or division will emulate these practices throughout their own care and work. Clinical ethics does not just stop once a conflict at hand is resolved. Staff can mimic these practices and develop a practice that is moral, ethical, and compassionate throughout the patient's clinical experience.[139]

II.a.iv. Conflict Management Capabilities:

Leadership is either within someone's being to provide a sense of direction, or it is born through training. Leadership will not work efficiently if the practice is not understood that it is based upon the groundwork of the organization's culture, principles, and values that are

implemented and maintained throughout the system.[140] The leadership team within the organization should be strategically picked by choosing people who encompass those values. The leadership then can sustain the organization's norms, values, and services that supports the mission of the organization. Management as a whole should take on the role as the moral agents of the medical field that presupposes their leadership role as the oath to better serve their staff and patients.[141]

Conflicts arise when miscommunication, organizational changes happen within the team environment, or value disconnect occur throughout the medical care of the patient.[142] The responsibility of managing conflict lies on the medical team to identify the problems and influence possible solutions to the problem.[143] Medical members should be taught to identify these issues so that the conflict is resolved before the problem becomes more evident or drastic measures need to be taken to fix the conflict at hand. Mediation should also not involve force of dominance to achieve a goal rather a compromise between all parties involved to create a win-win strategy.[144]

In practice, conflict management skills are not self-trained rather they are taught through trained staff in conflict management expertise, direct instruction based learning, and ongoing training for quality effectiveness in a clinical setting.[145] If clinical providers are training their staff inaccurately by insufficiently teaching their staff to manage conflict appropriately, then it is the duty of the organization to uphold their standards by implementing quality training sessions to better acquire the student teacher relationship within the clinical learning experience. Clinical staff learn from their preceptors and management. If the higher level of authority is inaccurately teaching the trainees, or not teaching at all, then conflicts will arise more often. The fact of the matter is that the relationship of management to resident, nursing staff, nursing aides, and other

clinical members is executed based upon the understanding of conflict management under different circumstances in any given situation.[146]

All clinical programs should increase their education taught on conflict management, and make remarkable changes to improve their programs if conflict management training does not exist. Conflict management alongside improved dialogue, and proficiency in medical care attains a higher status of quality care for all persons involved. If medical personnel are taught this training in their medical programs, they will be better equipped in the field, and can then see their training at play during a real life situation. However, if conflict management is not initially taught before seeing it first hand in the clinical setting, it is hard to dissolve a conflicting issue without some proper knowledge, or skill. Medical ethicists can also assist in teaching, and continuing education with clinical staff members on conflict management and how to use their skills to either prevent or manage the situation at hand.

Increasing the support to improve team function is based upon: prioritizing specialty involvement, providing appropriate time to manage the conflict, ensuring training for proper communication to manage conflicting situations, and embedding education for quality functioned team based care.[147] Conflict management is built around the solidity of the clinical team. If conflict arises within a patient's care, it is the duty of the medical team to provide care within the patient's best interests and manage the conflict without delay. Team based healthcare is fundamental to the success of the provided skill, training, and implementation of the healthcare organization's foundations and management teams. Ultimately, the team, the family, and the patient are there to work together to achieve a shared goal that reflects the patient's wishes or best interests by collectively managing the conflict by skilled clinical professionals trained consensus building or conflict management practices.[148]

<u>2B. Core Competencies Applied to Case Analysis:</u>

The adult realm of medical care is not the same as the pediatric realm. Medical ethics cannot base their whole entity on adult ethics consultations. There needs to be a quality controlled ethics consultation based upon pediatrics so that care can be curtailed to the child patient rather than the proactive adult patient. Pediatrics focuses on surrogate decision making and best interest standards. Adult ethics consultations focus on patient autonomy and patient values. Child patients do not have autonomy nor standard values at such a young age, than adults would have later in life. We cannot ask them what they want at all times like we do with adults.

The core competencies for ASBH involve particular competencies for an ethics consultant to be an expert and recommend particular ethical suggestions to proceed in clinical care. These recommendations are based upon proper knowledge of ethical literature, framework, standardized care, ethical duties, responsibilities, and actions based upon ethical theories and practices in ethics. The above differences in adult versus pediatric care will help better understand the reasoning behind the case analysis. These will be more defined through a case based approach through core competencies and ethical framework.

There needs to be a driven standard to showcase the differences between adult ethics and child ethics in order to create quality ethical healthcare in pediatrics. Ethics drives quality care. It is especially needed in pediatrics when such care is usually driven between physician paternalism and parental rights. It is hard sometimes to remember that there is another human involved, even though at times, they may not be able to voice their rights. Best care approach for ethics consultation and pediatric medicine is implemented by including patients, medical teams, and the ethicist to develop a higher quality treatment plan agreeable to all parties in the best interests of the patient.

II.b.i. Surrogate Decision Care Vs. Patient Value Centered Care:

Patient value centered care is usually the ethical analysis and problem solving technique in adult medicine. Holding the respect for autonomy as the principle value featured as the most important in adult medicine practice helps navigate the patient's values into medical care wishes that also appropriately involves the friends and family during end of life care.[149] It is easier to make decisions in adult medicine because the adult can make the decision based on being informed with a complete profile of information about their care and treatment options. In pediatrics, especially with neonates and young children that don't necessarily have the means to express know or understand what their needs or wants are to be able to communicate them makes executing their wishes or express their values to the medical team difficult to impossible because of their age thus experience level to draw upon. Rather than a patient value driven care that a physician is able to present all medical options and the patient can make their decision based upon expert knowledge, the physician is speaking with the surrogates or in most cases the parents of the child.[150]

Children from an outside perspective have very little autonomy. Acts can be autonomous by degrees. This means that there are degrees of understanding and control. There are many decision making areas such as, surgery, treatment, medication, trial studies, and end of life care that a child may not fully understand. The "control" degree pertains to these said situations and depend on the patient's level of understanding and their ability to control the outcome. The child may or may not be able to control the path in which they want to partake, and instead, whether they understand the situation or not, their outcome is fated for them. Children from all points of life go along a spectrum of being in control and not being in control; they exhibit different degrees of autonomy as their understanding develops.[151]

In some cases, the act of autonomy is overcome by the act of surrogacy. A surrogate decision maker is someone who makes the decisions for the patient. These decisions are usually made because a patient is incompetent. This means that the patient is not in the state of mind to make sound decisions. The patient however should never lose all moral protection and moral respect during this time of incompetence and should always update the patient's moral status, rights and obligations when concerning a surrogate.[152]

The surrogate should act on grounds of knowledge. They should understand the patient and wishes of the patient. There are many requirements with which the surrogate must comply when deciding on treatment or care actions. The surrogate decision maker must be competent to make reasonable decisions; possess acceptable knowledge and information; must be emotionally stable and be dedicated to the patient's best interests.[153]

Surrogate decision making in pediatrics encompasses the best interest of the patient so that the most idealistic treatment options are presented and shared together with the family, patient if possible, and medical team. Shared decision making amongst this triangle should be guided by the ethical principles of autonomy, beneficence, non-maleficence, and justice by respecting the parents and child's views or suggestions alongside the medical team's expert opinion.[154] The values of ethics should drive care during surrogate decision making. Even though the child patient may not be able to be fully autonomous in medical decision making, the child patient should benefit from the medical procedures, be in their best interest, and be treated like any other child patient in the same situation. These principles should guide care not as if they are in the adult world but they should be agreeably changed to fit the standards of pediatric medicine. In pediatrics, there is a collaborative care approach in which the partnership between the patient, family and medical team facilitate care based upon the informed treatment options,

finding understanding of concerns, and agreeing upon a plan of action that best fits the needs of the patient.[155]

The multi-disciplinary needs of the patient are defined by the personalized approach in each and every individualized patient assessment of care (porter 517-519). Every patient will have a different medical case even though they may have the same exact diagnosis, the patient, the family, and the medical team will need to work together to configure a plan of action that will not be exactly the same as a patient with the same disease. Ethics develops the case as a whole including the patient and family needs, values, and wishes. The disease is the center of focus, but the involvement of the team centers each individual's care on the goals, preferences, and customization expressed by the team, patient, and family.[156]

Most of the time the child patient's best interests are determined by one on one conversation with the patient if applicable or with the parents of the infant child. The best interest's standard requires the surrogate's decision to promote the patient's best interests by: promoting the patient's welfare, making choices namely about relief of suffering, preservation or restoration of function, and the extent and sustained quality of life that reasonable persons in similar circumstances would be obliged too.[157] However, this standard is scrutinized because the individualistic knowledge from the child is unknown, vague and can be open to dangerous abuse.[158] The best interests of the child should take into account all specialty physicians, nursing staff, care teams involved, and make the best interest standard as a team effort. This standard should give direction to the current medical situation and promote the maximum good to the individual patient at hand by focusing on the multiple alternative options, minimizing net harms.[159]

II.b.ii. Care Ethics Vs. Ethical Framework and Patient Autonomy:

Patient autonomy is one of the most important principles held in bioethics. It is the principle of self-expression and self-choice. Autonomy is correlated with identity.[160] A patient makes their medical decisions based upon their values that they uphold in their everyday life. The things that are important for them and drive their character should also be a part of the medical care if the patient cannot speak for themselves. In adult medicine, autonomy plays a crucial role in decision making. The medical team proposes options of medical treatment and the patient makes an autonomous decision.

Respect for autonomy is a duty and not a meager ideal in health care.[161] This obligation is to the patient and to refuse them of this right would be to decline them their respect of their person. The premiere necessity is to respect a patient's autonomous choices, of any kind there may be.[162] No matter what the outcome is, the physician should respect the patient's wishes. All theories of autonomy have two conditions. These two conditions are liberty in which the patient is independent from all surroundings and agency which is the capacity for a deliberate act.[163] These two conditions create the space for a patient's own thoughts and magnitude to engage in an intentional reason for certain procedure, treatment, or surgery. An autonomous person is also aware and able to process, select, and permit on goings of their medical stay.[164]

If any profession is normatively good, any relationship will require professional good or virtue.[165] Rather than autonomy surrounding adult medicine, in pediatrics the focus is based upon best interests and care ethics. The profession of ethics in pediatric medicine requires good moral virtue stemming from an individuals' character and the children's system itself to develop a 'care ethic'. This ethic should perpetuate through the system by the time a patient comes through the doors of the medical facility. This ethic should be embedded into the care of each individual child and should embody the virtues of compassion, empathy, trust, respect, and faith.

The focus of care should be a moral quality in itself so that the ethics of care can guide us to what is morally acceptable and what is morally wrong.[166]

Ideally if medical professionals could be taught to act ethically and morally just then patient care could always be attained at a just level. However, we do not live in a perfect world and we do not always spend the time or exchange the information so that we change the care provided in medicine. We do nevertheless have ethical framework, education, and proactive clinical ethicists to help guide the appropriate medical care for pediatric patients. In the perfect medical world, physicians and nurses would theoretically have a list of each skill, values, virtues that would achieve the desired physician or nurse, and this would optimally attain the goals of ethical medicine.[167]

In the present medical arena, ethics may also be considered 'virtue ethics' which will guide pediatrics to attain the goals of ethical medicine. This type of ethics requires qualities that are necessary to achieve excellent internal medicine and attaining the best for humans as a top priority above all other circumstances.[168] The human being and in this case the child is the most important priority to the medical care team. The virtuous acts that an individual possess comes from within a person's true character that drives their views, opinions, and actions. Virtue is one of the oldest and most durable concepts of ethical theory. These virtues cannot be easily separated from the reason, emotion, and practical judgment a person must use to take action to resolve a problem.[169]

In order to value care ethics, the concept of empathy should be set in the forefront of care when accommodating the needs of the key role-players in difficult conflicting ethical situations.[170] This is an absolute in ethics. The concept of empathy should be intertwined when difficult situations arise because no one knows what the other person is going through. People

are inherently different. This should be respected by being empathetic towards parents or surrogates that are living through their child's life altering medical situation. No one's pain is the same and in that instance all a person can do is be empathetic to their individualized situation. Understanding and wise judgment helps identify the emotional complexity of the particular situation and acknowledges the motivation of the personal concerns, vulnerabilities, and problems arising because of a person's deepest fears by being flexible in assessing the situation.[171]

There is a therapeutic goal to care ethics to heal the conflicting situation that poses what moral judgments should be made for the patient's optimal treatment plan. Care ethics entails the ethics consultant to bridge moral norms, virtue ethics, ethical frameworks, and constituted medical judgment to engage the therapeutic goal. The concept of justice and virtue ethics cannot stand on their own and require ethical theory and moral philosophy to withstand the scrutiny of medical science to ensure what is rightfully owed to the patient.[172]

The virtue ethicist is able to register their feelings of their human experiences and be able to approach ethical dilemmas by stripping away emotional responses to reason with a plausible solution that is developed through being a pivotal moral agent for the patient at hand.[173] This moral agent who processes ethics consults is ideally a key figure to promote the wishes and best interests throughout their medical care for pediatric patients. This ethicist for pediatrics should not only use the care ethic model, but should also intertwine an ethical framework. Ethicists should approach the particular situation with moral reasoning, sensitivity, and right action to manifest care.[174]

<u>2.b.iii. Case Analysis:</u>

Ensuring case analysis is properly critiqued, the ethics consultant should identify the ethical issues by relating the ethical methods and competencies to derive a normative method for the ethical implication at hand.[175] They are able to derive ethical expertise into the real life clinical practice. The role of the clinical ethicist can develop and maintain the ethical practice of ASBH standards and core competencies and focus on the responsibilities of the knowledge and skill for developing an ethics program or newly engaged ethicists.[176] The clinical ethicist uses the moral competencies to teach moral theories and philosophies of ethics in real life situations.[177]

For example, early pre-term pregnancy happens all too often. This is neither a calm nor ideal situation. The case brought before us, is a twenty-five-week old newborn baby girl who was pre-term because of a placental abruption which led to the child having to be delivered early, and upon delivery, the child needed active resuscitation and was required trach placement with mechanical ventilation.[178] After watching the newborn for a period of time, the physicians warned the parents that the baby has suffered a large unilateral intraventricular hemorrhage with evidence of parenchymal infarction.[179] This means in non-medical terminology that the child had bleeding in the brain in which the patient's brain tissue dies due to lack of oxygen that area of the brain receives. Therefore, in this type of patient, there is a high possibility that the child will develop cerebral palsy.

In this case, we cannot ask the newborn whether she would want to live or not. We cannot ask her if she would want to live with a disability. It is hard in pediatrics to make decisions based upon medical knowledge, and non-foreseeable events. The physicians are basing their diagnosis upon medical fact, and possible outcomes. They note that the child will be

disabled, but then the question to ask is to what extent? Can we provide for this child? Is it a good quality of life? Do the benefits outweigh the harms?   These are just a few questions the medical ethicist may be thinking at the time of the consultation. There is a larger picture than the initial diagnosis of the disorder. The physicians may see only the disorder, but the parents are thinking about the social, mental, and physical capabilities that the child may now have to overcome. Let's take a step back, and diagnosis this case from the time the parents find out that there their child will now have a disability, and one parent wants to withdraw treatment and the other parent wants to do aggressive treatment. An ethics consultation is now placed, and we begin our endeavor on the clinical ethics consultation in a cerebral palsy newborn.

First, the medical ethicist needs to gather all the information about the case. The newborn patient is diagnosed with cerebral palsy upon pre-mature birth. The parents are in disagreeing about care. The physicians have seen many cases like this and children usually live to be between their thirties and fifties. These children may just require more care, and a higher level of care to optimize their life expectancy. Once information about the child's defect is noted, the parents and the physicians should sit down with the team alongside the medical ethicist to discuss options for the infant.

Essentially, there are two routes that this case can go in. The first, the parents could forgo treatment in the case that the baby has a devastating life altering decrease in mental status or other organ failure within the baby's course of care. The second, the baby has a good prognosis and they continue treatment, even if the baby may have cerebral palsy. Parents, nor physicians, in the state of Pennsylvania can forgo life sustaining treatment just because the child will have a defect. The child can still live thirty to fifty years, and may not be the quality of life you or I have experienced, but there are ways to make their life of quality. The Disabilities Act

of Pennsylvania states that children who are born without decisional capacity, or substantial cognitive ability should be assumed that they would want all life sustaining treatment up until death is imminent and parents or other surrogates can then withdrawal care. There is protection for people with disabilities, and that legally, and ethically should be respected.

Beyond such terms, it is the medical ethicist's responsibility and medical team to inform the parents of all options whether that be adoption or facilities that are equipped to better care for the child if the parents cannot. The standard of care is to give the families all viable and feasible options, informed information about the prognosis of the child, and support after hearing their child is not going to be "normal". The second ethical opinion is that everything should be done in the best interests of the patient. The medical team, ethicist, and family should all work towards the goal of best possible outcome and care for the child patient at hand.

II.b.vi. Best Standards Care Approach for Ethics Consultations of Pediatric Patients:

The core competencies are extremely active in a case based approach. The value based approach that should be used in clinical ethics consultations should satisfy the patient's intentions, beneficial treatment, and long term success in their clinical interventions.[180] The value based care approach centers around these core competencies and states that ASBH rules clinical ethicists be involved in their patient's care. By doing so, the ethics consultation becomes patient and family centered and includes the collaboration of the healthcare team and partnership of the patient's values and medical innuendos as noted previously, but are supported now because they are done with the best interest of the patient because all are involved with obtaining the patient's goal.[181]

The conflicts that typically reside in clinical ethics situations usually deal with autonomy patient rights issues, beneficence of the caregiver, tensions between justice and autonomy or self-interests.[182] The consultant can differentiate between ethical issues or conflict, moral distress,

patient satisfaction, or family disbelief rather than entertaining non-objective "ethical" ideals. The role of the ethics consultant can thrive on the basis of normative theory, principals, and the core competencies that are morally justified through right and wrong so one takes the right action to manifest quality care.[183]

Whether the medical care is centered individually on the patient, there may still be conflict. This can emerge when patients, surrogates, or clinicians differ in the goals of care for a patient.[184] Some professional staff may not be equipped with the skills or competency in conflict management to appropriately handle the situation at hand. The effective assessment and interpersonal skills alongside negotiation facilitation counseling advocacy, mediation, and debriefing are all required in order to be competent in conflict management situations.[185] Ethics consultants would be able to resolve conflict, and debrief staff on how to handle a current situation and similar situations for the future. Unresolved conflicts create barriers for patients, families, clinical teams, and clinical staff and don't allow for productivity or integration of care management.[186]

One of the hardest choices about making a choice in a child's treatment is simply making a decision. It is sometimes difficult to distinguish what is possible from what is ideal because what is possible may not always be realistic.[187] Every clinical diagnosis is different, and no two cases are exactly the same because every child patient is different. It is hard to mold "miracle" cases and "once in a lifetime" cases into a consistent reality. Parents have difficulty understanding that sometimes medicine and science can only be extended so far before possibilities are no longer possible. That is why the best interests of the patient should be based upon what benefits the patient in realistic terms. The team should evaluate and weighs all the treatment options to maximize these benefits and present them to the decision makers because

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the obligation of the surrogate or of the parent in most situations is to understand and evaluate the weighted benefits so the child patient inherits the highest net benefit possible from the team, and then the best decision overall for the child patient can be made.[188]

It is hard to override parental authority because the medical team must establish that there is direct harm being done to the child or the child is in imminent danger of harm.[189] The best interest's standard also is a duty to the clinical team to best manage the patient with their duty to beneficently care for the patient. The obligation of the surrogate and the healthcare team is to best ensure that the patient is not harmed. The choice is simple. The shared decision is based upon standards of care, best interests, and empathy for the patient and family enduring the difficult medical journey.

III. Conclusion:

Ethics consultations will improve quality care and standards within a hospital system. The role of the ethics consultant will express quality implementation within disorganized or miscommunicated care. Explaining and documenting ethical theory will determine dignified and just care based upon patient values and goals of their personalized medical care. This can be easily implemented based upon a preventative approach to medical care by a preventative ethic within the organization's culture. The culture of the organization should expound the values and ethic of the organization through their employees on a daily basis. The interaction between medical staff and patients should exude the just practice of medicine that is sensitive to patient needs and values. Preventative ethics will transform the new age of medicine that has been lacking in quality patient care. Ethics consultations are also preventative in the way that they prevent multiple readmissions to the hospital. With effective ethics service, patients will be discharged quicker, add more effective communication, alleviate moral distress, integrate quality

care teams, and reduce costs to patient and healthcare systems. This service is a multi-dimensional service that is needed to redefine quality patient care.

The implementation of ethics consultation services in medicine drives healthcare quality. Pediatric medicine is based upon adult medicine. Pediatric ethics can have their own ethical construct curtailed to pediatrics alone instead of a downsized ethics program based off of adult medicine. Pediatrics ethics consultation is based off of the ASBH core competencies, and surrogate decision making, with the essential concepts of beneficence, non-maleficence, and justice. Implementing quality pediatric ethics consultations will drive competent staff and best practice standards to improve the care for pediatric patients, clinical staff members, and families during a crucial time for the child patient and all involved.

The empathic counseling and consoling of medical staff and their initiative to provide information with understanding to the parents and or family of the child patient is a necessity in pediatrics. These values are not necessarily learned, but within a person. A training program can define and teach allowing for the best service for quality patient care. The communication developed throughout care should be informing with a sweet touch of empathy for the one's listening on the other end of tragic news presented. Pediatrics develops on its own an integrated team. Ethics then adds another layer of quality to the patient's care that drives the highest standards for the greatest possible gain for the patient. Ethics consultation services approach benefits not only the medical case providing best means to present and base recommendations, but provides the understanding, assistance to family concerns, and ultimately the best interests for the patient driving care. This will ultimately be acknowledged as the forefront to nuanced medicine.

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Chapter 3: Core Ethical Dilemmas in Pediatric Medicine:

Pediatric medical ethics can be considered overlooked. Pediatric medicine is very different than adult medicine concerning informed consent. Informed consent in pediatrics is practically non-existent. Parents of the child are informed of medical necessities and the child has the ability to agree or disagree with their assent. Their assent is not legally obligated for the physician to participate in medical care if the parents see it as necessary. There are many problems with consent in pediatrics. The ethical dilemmas are extraordinary. Pediatric medicine will be critiqued based on the moral justification of informed consent through ethical decision-making and health care ethic techniques. This will be shown through different characteristics of informed consent in pediatrics which includes: the historical analysis of informed consent, patient's rights principles, physicians' notion of informed consent, hard choices to consider, and lastly, patient assent in pediatrics.

End of life decisions in any situation is a complicated and overwhelming decision. A person does not want to make the difficult decision of taking their own life, let alone having the task to decide whether treatment should end for another person's life. The ethical complications of limits during end of life issues dealing with treatments and interventions in neonatology will be discussed throughout the essay. The debate at the end of life lies in the concept of futility. This concept is fairly new to medicine which was adapted from the new goals of medicine. These goals aspired from the attitudes of physicians seeing the can do everything attitude fade into the past to care does have an expiration.

The Catholic and Islamic traditions vary greatly within the ethics realms. The four principles of bioethics which include: autonomy, beneficence, non-maleficence, and justice will be explored within Catholicism and Islam which greatly differ based upon the sequencing of

ethical principles. These principles stem greatly into the patient physician relationship at the end of life. Symptom management at the end of life can mean achieving symptom goals by any medical means. Ethics consultations will improve this conflicting religious scenarios during symptom management and end of life care. The ethics team will be able to assess the situation and improve the quality of care for religious patients.

II. Respecting Family Consent and Minor Assent:

This Section will discuss patient rights movement, human rights in patient care, the good doctor and paternalism. These will be discussed in more detail within pediatric medicine.

II.A. Patient Rights & Paternalism:

Human rights and patient care rights have been brought about to universal standards. These movements have encouraged change in areas of healthcare that needed to grow. The concepts of patient rights are the foundations of bioethics. Human rights entangled with patient rights thus forms these justified principles that should be held to the highest standards even when dealing with children and pediatric medicine. Physicians have a different perspective of care than the patient does. The physician in general is the one providing care and the patient is the one for whom is being given care. The physician is held to an ethical standard when caring for a patient. There is certain criterion that needs to be met when a physician is tending a patient. The physician can show good qualities of beneficence and non-maleficence which should be acts of all physicians if morally justified. Paternalism may also play a role being a pediatric physician. These different concepts either are perceived as a good doctor or a questionable one depending on how they are used in medical care.

II.a.i. Patients' rights movements:

The patients' rights movement was a difficult movement to generate.[1] Most patients are too transitory to feel fully involved in the process and some would rather forget their time in the hospital.[2] However, this movement would be the key for striking the development of the Organization for the Protection of Patient's Rights: The National Welfare Rights Organization (NWRO). The NWRO completed twenty six requirements in order to protect patient rights.[3] In 1972, American Hospital Association approved the Patient Bill of Rights that disclosed patients to their privacy of all medical information, explanations of their bills and medical treatment, and lastly it also included many other atomically appropriate rights.[4] Doctors wanted their patients to be able to trust them without having to go to the lengths of law. Some physicians saw this bill as a sign of doubt between their relationships with their patients.[5] All in all, the outcome of these organizations is for the good of the patients.

There are many patients' rights that are very important to be discussed. These rights are: the right to autonomy and self-determination, the right to privacy, and the right to treatment.[6] The most important concept of patient's rights is the right to autonomy. This means that a person has the right to make medical decisions with their own freedom of choice. The right to self-determination explains their right to accept or refuse medical treatment.[7] These two principles act together harmoniously by the autonomous choice to choose their decision and to be able to accept or refuse treatment. Congress passed the Patient Self-determination act which makes sure that all providers inform their patients of their right to accept or refuse medical treatment and their direct right to execute advance directives.[8]

Along with the right to autonomy comes the right to informed consent. This is the ability to make decisions based on the amount of information given to the patients by the physicians and

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medical staff (US legal). Before consenting to any treatment options a person should receive

certain information to make an informed decision about medical care. People have the right to

know what their diagnosis, nature of the condition and the risk of harm to the patient or others

is.[9]

The fifth and fourteenth amendments to the U.S. Constitution, protects people from

unwarranted invasions of privacy and promotes confidentiality.[10] Confidentiality between

patient and doctor is an important disclosure that should be upheld to the utmost privacy. Any

information learned or gained by a physician during an examination with a patient is privileged

information.[11] There is only a duty to divulge patient information to other sources if there is an

absolute threat to others or the community at large. In many states, if an HIV/AIDS exam comes

back positive then most states must report them. There is a duty to report to health authorities or

third persons if there is a threat of harm to other persons.[12]

All individuals are entitled to hospital emergency care. This means any individual

without health insurance is due their right to be treated in an emergency situation. All patients

present with an emergency medical condition need to be treated until medically stabilized, no

matter if they can pay for their visit or not.[13] They also have the right to refuse treatment and

leave the hospital at any time of their stay.[14]

These rights are due to every individual in the United States. This includes minors. A

child has the right to autonomy, informed consent, and treatment. The child has these rights that

are stated in the US legal system. However, the legal system deems that parents are the co-

decision makers dealing with their children in medical terms. There needs to be a mutual respect

between what the patient and parents want relevant to the care of their child.[15] The child does

have an autonomous right to a decision and can assent to certain treatments if in that child's best

interest. A child can refuse to inform their parents of certain information discussed with their physician dealing with privacy laws.[16]

II.a.ii. Human Rights in Patient Care:

Human rights require three interrelated qualities: rights must be essential in humans, rights must be equal for everyone and rights must be universal.[17] Human rights should be based on the mere fact that everyone is human and should be treated equally.   Human rights also possess the quality that every individual has their own ideas, thoughts, and knowledge to create their own rights. Rights remain open to question. Human rights are always changing. They continually pose the question of who has earned those rights and who deserves them. This question is still being posed to this day. Human rights should always be questioned when they are not universal, equal, or natural.[18]

There is a correlation between obligations and rights.[19] Obligations such as: do not kill, do not cause pain or suffering; prevent harm from occurring and tell the truth correlate directly to those basic rights. The basic rights of these actions are said to be: the right to not be killed, the right to not be caused pain or suffering by others, the right to have harms prevented from occurring and the right to be told the truth. These actions are obligations and rights; just the wording of these actions separates and prohibits them from one category to the other. The language of rights is translated into a language of obligations that need to be upheld.[20]

Article eight of the UNESCO declaration discusses the rights of human vulnerability and personal integrity. The UNESCO document pertains to all human beings and should be upheld to high standards all around the world. Every human being is vulnerable at one point or another. Each human being has a vulnerable state, and every human being can be exposed to

vulnerability. It is important for individuals to understand that every human being is vulnerable, and that they are not exploited or abused because of the diverse levels of autonomy.[21]

Every child's autonomy is endangered. Their freedom to choose and to speak for themselves is always questioned. Children themselves are vulnerable. Their actions are predetermined for them by their overseers. Children are a vulnerable population who can have their choices and actions swayed by dictate of parents. The vulnerable are people who have little autonomy, dignity, or integrity, and are capable of being threatened.[22]

Human rights and the recognition of dignity are adherent to all human beings. To deny someone their right to dignity is to deny them of life. Each person has an innate self-respect that without the recognition of dignity, a person lives without soul, without life, without happiness. No person can make a decision without their dignity intact. There is a foundation of freedom, justice, and peace which is the heart of international human rights around the world.[23]

UNESCO's declarations, Article Three: Human Dignity and Human Rights, explains the rights of all human beings that are well deserved and should be respected. Human dignity is inherent in all human beings. Each human being may have differing degrees of human dignity. Children may have less because of their understanding of the world itself. This does not mean that adults have a greater understanding of the world, but may have learned more understandings throughout their lifetime, which children have not gotten the chance to achieve yet. Regardless of their age, all human beings deserve the utmost respect.[24]

Personal autonomy as well as integrity and dignity should be respected equally. All of these principles coexist together in the fight for human rights. These principles do not just pertain to adults because some adults lack education, diversity, connections to science, the arts, and developed medicine which without this knowledge one could say they are just as

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incompetent in knowledge as a child is. A child is born with no knowledge of anything, but an adult will only obtain the knowledge if they are led in the right direction. Each child should obtain the right to justice and freedom for their autonomous choice in the matter of their care. A human being with a legitimate claim, based on the principle of justice has the right, and is therefore due something.[25]

II.a.iii. The Good Doctor:

Physicians live and abide by certain rules and codes of conduct. They must help, consider, and above all else save their patients' lives to the best of their ability. As, long as humans are alive, they will become ill and need the profession of physicians for help. Physicians have gone through schooling of medical knowledge to which the patient chooses them to guide them in the medical world. Patients depend on physicians to explain, to be trustworthy, to respect, to care and to interpret the medical terminology which the patients do not have the knowledge of. This code that physicians are bound by, they have voluntarily proclaimed allegiance to the code which they are obligated to defend morally for their patient's sake.[26]

Beneficence is the moral obligation to act for the benefit of others. This can be controversial because many acts of beneficence are not obligatory. The act of beneficence is obligatory pertaining to physicians. Physicians must act beneficently to their patients and act with the most benefits to the patient. It is their duty to preserve life if circumstances allow the life to be saved. If the physician has the possibility to prevent something bad from happening, and mustn't sacrifice no matter which of equivalent importance then it is their duty to morally do it.[27]

Many people outside the healthcare field use duty of physician as their duty of beneficence. Beneficence is doing good by another. It does not contest to say that the duty of a

physician is to be beneficent. The duty of a physician is to care for another human being or patient, but to lump in the duty of beneficence is a misconceived notion.[28] All people have a duty to do good by one another and to not produce harm to one another. That is a moral rule for all people. To say a physician to do their duty is to care for their patient and beneficence is entailed. There is confusion when a physician needs to have a duty of beneficence to do their duty of beneficence.[29]

Non-maleficence is defined as to do no harm. This concept is intertwined with the concept of beneficence. The physician must be beneficent to their patient by promoting good actions and benefits to the patient. If the physician promotes good actions then to do no harm is not a problem. However, if a child needs surgery because they have a mass in their leg and once in the operating room the physician sees that they need to amputate the leg of the child to save their life in the long run, then the physician has done harm. The physician was beneficent and promoted the well-being of the patient, but was non-maleficent by amputating the child's leg. Now, yes the procedure was technically non-maleficent, but it was justified because a life was saved, and the intention was to save the life of the child, not to amputate the leg. Harmful actions with the patient's best interests at hand are justified actions and not wrong.[30]

Physicians should have a tight knit relationship with their patient. In pediatrics, it is not only a physician patient relationship; it is also a physician, patient, and parental relationship. Having all these people involved in medical decisions can make it a challenging situation. The physician must stay beneficent to the patient or in this case the child. One of the largest obstacles of being a physician in pediatrics is trust and safety. Trust is apparent. The parents need to feel that everything is being done for their child's care. The child needs to feel a sense of safeness. The obligation is to the child, but there is no consent to medical treatment without the

trusting relationship of parent and physician. The physician is obligated and loyal to the patient, who has trust in the physician to maintain the primary interest of the patient's wishes upheld.[31]

The physician must also have a moral heroism and possess all the morals and ethics while working with patients.[32] However, the physician should be careful to not be considered a saint. A moral saint consists of the physician that has exceptional altruism, benevolence, and prominent features of other directedness.[33] The physician does show these characteristics, but not to an exceptional defying manner. The physician may be considered a hero in certain situations, but they would have to undergo risky situations to provide care and people would draw a moral obligation from them.[34] However, most physicians do not put themselves in risky situations and usually will have to protect themselves and then protect the patient in hazardous situations. A child or parent may view the doctor as a saint or hero. The physician is trying to save a life and most people especially children would view them as a caped hero. As long as the hero, hence the physician, shows exceptional values and morals all the time no matter what circumstance when dealing with a patient.[35]

The physician has choices and decisions to make in a split second, or has ample time to decide on a course of action for their patient. This can be difficult, stressful, and overwhelming for a doctor to make these decisions pertaining to a child's life. The moral judgments and values of the physician and duty to their patient will in fact lead them to the correct moral judgment in making their decision on patient care.[36]

II.a.iv. Paternalism:

Beneficence is a part of physician paternalism. Beneficence as stated before has a level of trust that is instilled in the relationship of the patient with their physician. The patient fully trusts that the physician will be involved intimately in the care of their health. The physician's

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beneficence is not merely the paternalistic willpower to do good by the patient; it is more so for the physician to take the patient's values into the well-being of their care.[37]

Paternalism was formed from the aspect of a father figure. This concept treats the physician as the father which would control the situation in the patient's care. The physician would choose the direction of care rather than allowing the child to make their own autonomous decision. This concept can take away the autonomous act of the child's ability to choose freely their path of care. The physician in turn chooses the best course of care according to his or her own ability and judgment.[38]

The physician in paternalistic acts may seem to be non-beneficial in terms of morally respecting the patient's wishes. The patient may want one thing and the physician will do another. The patient's wishes are supposed to be held to a higher standard and the physician should do everything in their power to respect, and carry out those wishes if medically possible. Their duty is to the patient who should benefit without their wishes being overridden. Paternalistic acts may not be noticed at first because they are in the form of deception, lying, manipulation of information, and coercion.[39]

A physician may see deafness, blindness, or speech impediment as a malfunction of the body that can be easily fixed. These types of disabilities could be considered imperfections from a physician standpoint. Some physicians want to fix these imperfections because they feel the need that these children come into this world with hearing, sight, and communicable capabilities. The fact that these children do not have these capabilities empowers the physician to take the paternalistic role in order to fix their disability. Physicians may see flaws, incomplete, or dependent of others as an implication that can be fixed and they have the authority to do so, to

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override, and to make the suggestion of capabilities over deafness, blindness, or speech impediments.[40]

There can be justified paternalism when information is withheld and not formally informed of the consequences. The physician may act in this way because they do not want to alert the patient before they really need to be alerted. The patient may act in an unnecessary way, when the physician does not want them to panic before it is necessary. In the case of pediatrics, the physician may not want to worry the parents before they are one hundred percent sure of the diagnosis. The physician then will be one hundred percent truthful with the parents and patient after all tests are complete and all information is discussed to decide the next step of care.[41]

Children have certain wishes and expectations of their care that may not be protected in paternalism. The physician sees their views as detrimental to their health, or they feel that they may have a better way of going about their care. Hard paternalism can prevent the child from free choice and action. Their autonomy is hindered in the process. Soft paternalism is an easier concept to justify. Soft paternalism works on the grounds of beneficence and nonmaleficence, but does not justify the fact that the actions of the physician include poor informed consent, or refusal of important information. Soft paternalism tries to avoid consequential actions that the patient chooses, but the child did not choose autonomously.[42]

A child may decide to end a treatment, to end an agonizing pain, or to die. The end of life care decisions may cause the physician to step in and use a paternalistic approach. A physician does not want to see the child make this decision when they want to do everything in their power to save their life. However, the child's choice should be upheld and respected above all else. They are competent and aware when making this autonomous decision. If the physician

chooses otherwise, and coerces the child into another direction, this hard paternalism is acting beneficently in saving the child's life, but loses all autonomous respect.[43]

A child has a voice to which they want to be heard in the decision making process. The duty to the patient from the physician perspective is to act in the best interests of the patient, to do good, to act with no intentional harm, and to fight for their rights as a patient. The patient in turn must trust the physician and be able to make their autonomous choice by the information given to them. A restraint of the decision may be necessary when a patient is not thinking clearly and trying to harm them self. This is the only exception so that their autonomy stays intact. As soon as the temporary restraint is no longer needed, the physician must take a step back in the paternalism role, or the restraint cannot be morally defended.[44]

A paternalistic behavior must only be used if it is in the use of the patient's best interests. If there is harm that can come of a patient then the physician can use paternalistic behavior to protect the patient. If a child is trying to get out of their bed or chair constantly during the night, it would be in their best interest to restrain them to the chair or bed so they do not harm themselves. The paternalistic behavior must be done with good intentions and for this decision to be morally justified.[45]

II.B. Minor Assent & Autonomy:

Informed consent is important in medicine. Informed consent in pediatrics has two dimensions. The patient is the child, but informed consent is given from the parent. Autonomy is an important concept attached to the concept of informed consent. An autonomous choice can only happen if informed consent is given. Surrogacy plays a role in the decision making process. A mother has a very strong bond which cannot easily be broken. This is where tendencies of consent and autonomy are made by the parent instead of the child. Children do not have the

legal right to choose for themselves. Parents and physicians have the legal right to choose for them. Children are considered underdeveloped in the sense that they have not lived long enough to develop certain understandings of life. They do not have the same knowledge that adults have in order to make proper medical decisions. However, assent should be more prominent in the field of medicine. This allows a child to have a stronger voice in the matter of their own medical dilemmas.

<u>II.b.i. Informed Consent Defined:</u>

Informed consent is a simple meaning, but is a very vital part of the medical process involving treatment or medical research. This informed consent in pediatrics will involve physicians, the patient, and parents. This concept is beneficial for the patient to be acknowledged by the medical staff and parents to make sure the patient understands the process of their treatment. Informed consent is the individual's autonomous decision of medical interventions or participation in research.[46]

There are certain elements of consent in order to reach true informed consent. Competence, voluntariness, disclosure, recommendation, understanding, and authorization are the elements of informed consent. Competence is the capability of choice and decision making. Voluntariness includes the individual's free choice without coercion or threat involved. The capacity to voluntarily consent is essential.[47] Human consent must be voluntarily offered in order for any procedure to take place. Every individual involved in the process must take some responsibility for the decision. If the consent is given due to force then this is not true voluntary consent. People lacking this ability are seen as incompetent.[48] The incompetency of a patient lacking the capacity to consent should be respected and advantage must not be taken. Care givers and other decision makers should be brought in to assist making the proper decision. This can be a standard safeguard for people who do not have complete competence to consent. The

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physician will provide different recommendations so that individuals can decide the best choice for themselves. The individual must understand the process thoroughly, the before and after of treatment, or medical research. Authorization is the final step which is the approval of the treatment plan from the patient's own autonomous choice. This consent factor allows authorization and ultimately permission to proceed.[49]

Most people do not understand the medical terminology during their stay in the hospital. People usually converse with their physician on some ground that they can understand. It is the duty of the physician to disclose vital information to the patient in such a way that the patient may make a choice for their next treatment phase with understanding. True consent is the individual's informed action of choice to weigh the risks and the options available.[50]

Informed consent may also be considered a part of a social structure. This structure may cause the downfall on pediatric consent. The social structure consists of laws, authorization, and rules that will overrule the consent of a minor. For instance, a minor who decides to consent to a risky procedure which the outcome is probable of death, would be in the limits of the social structure. The rules and regulations of society can however override the minor's decision of care. The authorization of the minor's consent will not be effective under the existing rules of society.[51]

In some cases informed consent is not realistic. Emergency and vital situations may not pose enough time to receive informed consent. In this case, the physician will do what is best for the patient to save the patient's life. There is no parental consent or patient consent when there is a life threatening situation and time is of the essence. If the patient is confronted with a life-threatening situation, if the patient has the inability to communicate, if the patient's legal representative is not available and there is not enough time, or if there is an available method to

save the patient's life then these weighing options are rightly chosen ethical choices due to the fact that the life of the patient is the most important piece in the situation.[52]

II.b.ii. Autonomy and Surrogacy:

Autonomy is an important right. This right for a patient should be respected at all costs. It is the individual's autonomy that must be respected and is crucial to sound decision making. Most decisions should be rational, but some may be irrational and made quickly, but as long as all information is given then full respect of autonomy should be experienced. There is no right held more sacred, or more protected by law, than the right of every person to the ownership and control of their own body, completely free of all limitations or intrusions by others, unless the sole person allows the interference by law.[53]

Simplistically put, autonomy is the freedom to choose for oneself. The self-determination, capacity, and competence of a person allow a person to be autonomous. Autonomy is the capacity to reason and the freedom to choose for oneself.[54] Both need to be present in order for someone to act autonomously.[55] A patient has the right to accept or decline treatment. The patient can accept or decline surgery, medication, physical therapy, or even something as simple as eating. An autonomous person has the right to choose any aspect of care for oneself. The respect for the person's autonomous choices is a required obligation, whatever the choice may be.[56]

Children from an outside perspective have very little autonomy. Acts can be autonomous by degrees. This means that there are degrees of understanding and control. There are many decision making areas such as: surgery, treatment, medication, trial studies, and end of life care that a child may not fully understand. The control degree pertains to these said situations that depend on the understanding and to be able to control the outcome. The child may or may not be

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able to control the path in which they want to partake, and instead, whether they understand the situation or not, their outcome is fated for them. Children from all points of life go along a spectrum of being in control and not being in control; they exhibit different degrees of autonomy as their understandings develop.[57]

In some cases, the act of autonomy is overcome by the act of surrogacy. A surrogate decision maker is someone who makes the decisions for the patient. These decisions are usually made because a patient is incompetent. This means that the patient is not in the state of mind to make sound decisions. The patient however should never lose all moral protection and moral respect during this time of incompetence and should always update the patient's moral status, rights and obligations when concerning a surrogate.[58]

The surrogate should act on grounds of knowledge. They should understand the patient and wishes of the patient. There are many requirements with which the surrogate must comply when deciding on treatment or care actions. The surrogate decision maker must be competent to make reasonable decisions; possesses acceptable knowledge and information; must be emotionally stable and be dedicated to the patients best interests.[59]

There is a decision to be made whether a person is competent or incompetent. The physician and medical staff use their professional judgment in determining this decision. Law does not allow the physician to make this disheartening decision, but the physician is allowed to supersede decisions made by the patient if seen unfit. There is a fine line between competent or incompetent and there is no true person to decide this matter. There is no test that exists to distinguish between an incompetent and competent person.[60]

The physician should however have the best interests for the patient at hand, especially if the patient is a child. The child may be considered incompetent because the child does not

understand enough medical terminology or care in order to make an informed decision about their treatment. Parents in general should be the ultimate advocate for their child. The parents are the most invested person in the child's life and should provide the best decision for the child's well being. Parents are able to weigh the risks and benefits before making the ultimate conclusion. Parents have the legal and moral authority to make the decisions for their children.[61]

Some problems may arise when parents are the surrogates. One problem in particular may happen without clearly noticing the actual problem. A parent may decide on the next plan of action in care for their child based on their own feelings rather than their child's best interests. For instance, a child may be suffering from Type A disease, and there is a research trial drug on the market that can keep the child alive, but has some really bad side effects. The side effects include pain, seizures, lethargic, constipation, insomnia, hypertension, and vomiting. The parent however, chooses to enter into the research trial because the end result is their child staying alive, but at a price. The child has to burden the pain and suffering of the trial in order to stay alive for the parents. The parents may be the surrogate, but at what point is the parent choosing their wishes over their child's. The patient should be able to exercise the right to decide and to request that personal values be respected even though they may lack the mental capacity of understanding mathematical or scientific standards of society.[62]

II.b.iii. Patient Assent defined:

Assent is the child's alleged ability to consent to a procedure, medical research, or treatment. Assent takes in the consideration that a child has a voice and a say in what they do with their bodies. Children do not legally uphold their decisions, but they should have a choice in the matter of their care. Children want to assume responsibility for themselves and their expanding freedoms as they grow because their interests in their own medical care.[63]

Parents do have the authority to consent for their children; that is evident. This is only acceptable if the parent puts their best interests forward. The parent needs to make sure that they are adhering to the acceptable care their child deserves. The parent cannot consent to treatment, medical research options, or care that would put their child at harm because their moral authority is actually limited if these procedures are hazardous to the health of the child.[64]

Ideally for the child to take hold of their own decisions they must be able to understand the purpose, risk, and benefits they will endure.[65] It is important that the child understands the whole process of the medical endeavor in order to use their ability to assent. Each child has a different understanding and competency. If they understand their medical needs then they have the right to assent. This invokes their personal autonomous right to make decisions and involve them in their own care and decision making process with the physician.[66]

A conflict of assent arises in the aspect of the child assenting to a procedure or treatment and a parent not consenting. This also can apply the opposite way when a child does not assent to medical care and the parent consents to the treatment or procedure. In these cases, there are differing opinions in care. This makes the physicians or court's ethical values important when looking over the information and making a decision of care. The consent of a parent is legally the path that is taken, but then the physician faces the problem of going against their patient's wishes and affecting their patient-physician relationship.[67]

The patient-physician relationship especially in pediatrics is very important. The physician should address the patient more so than the parent because the child is the one being treated. There should be an open relationship which both parties can express their problems and understandings. Pediatric assent is there to empower the child and allow personal responsibility and freedom to make decisions.[68]

The problem with consent in pediatric medicine is that the patient does not have the ultimate authority. The patient can consent to the procedure, treatment or research, but it does not mean that the consent will take place. The parents of the patient can overrule their authority to consent. This is based on competency and capability of the patient. This is the grey area of whether a child can consent to their own medical endeavors. Children should be involved in their medical decisions and empowered to make choices to the extent that they so choose.[69]

II.b.iv. <u>Legally Competent Debate:</u>

There is no specific age that a child can legally consent other than when they reach the age of eighteen and that is considered a legal adult. Children are all completely different and have different levels of understanding. Most researchers see that the age of fourteen or fifteen children have enough knowledge and understanding to assent to medical decisions. There is always the problem of asking too much or too little of children.[70]

Children either can be asked to make decisions, but they will be overwhelmed and not intellectually ready to make their own decision or children can make an intellectually developed choice, but never be afforded the right make the decision because they were denied the opportunity to decide for themselves. There is this fine line that either inhibits authority of choice or denies that right. As children develop through their childhood they should become guardians of their own decisions and take the responsibility off their parents.[71]

The early stages of childhood, which include the ages of two and three, make it difficult for a child to assent to pediatric care. This age bracket is too young to make an educated decision in one's health. The bracket of ages six to nine have more knowledge and are able to ask more questions to be more involved in the decision making process. This however, does not give age appropriateness a direct answer. Through questions between the physician and child the

age bracket of seven to nine showed promise of having knowledge about their care and could understand the risks and benefits of their decisions.[72]

Throughout childhood children grow with intelligence in order to make their own decisions in everyday life. Their decisions are based on a certain understanding of medical terminology, when really an adult's understanding of medical terminology is slim to none. A physician needs to be able to talk with a patient and be able to make them understand the medical necessities during their care. There is no telling what a patient will understand no matter what age they are. It more so depends on the physician's determination to relay the knowledge of what they know to the patient in a way that they can understand it. There is no systematic way of knowing an age that a child can understand the medical information given to them.[73]

The parents are an important aspect of decision making since they are the legally respected as the authoritative decision makers. The parental role needs to be examined in terms of assent. Futility plays a role in terminally ill children or end of life care. Futility is treatments that will not help the end goal. A child could have had a traumatic accident that resulted in a terminally ill case. The physician realizes this is the case after testing. They can do different procedures, but no matter what they do, the child will not breathe on their own. After discussing this inevitable end, the parents still want everything done for their child. The parents still think that if these procedures are done then their child will live. This futility is hard to deal with. A death is evident no matter what procedure is done. The death of the child is evident, but the value and time before that end happens is a matter of judgment.[74]

Treatment is considered futile when the means of survival seems unlikely.[75] Parents cannot let go sometimes and allow the child to die. The actions of the parents are to protect, and care for their child in the best way possible. Their instinct is to do anything possible to save their

child and they may not understand in the moment that no matter what they do, their child will not live. The treatment would have to benefit the child more than the burdens for futility to not take place.[76]

Futility needs to be explained because it encompasses the concept of the parent's role during pediatric care. This role is to save their children from harm. The parents will guard and protect them from all evils of the world no matter what the cost to them. To understand the reason why parents intercept the assent of children is the reason of futility. No matter what decision their child chooses the parent will always want to do more, to do better, and to do what is best ultimately to save their child's life. The physician then can act using their best judgment to use futility and make the choice for the parents and child.[77]

III. End of Life Care in Pediatric Medicine:

This section will discuss what futility is, futility at the end of life in pediatrics, the do everything attitude, and care that physicians cannot support any longer. This will be discussed in further detail.

III.A. Futility vs. Inappropriate Care & the Goals of Medicine:

A continuing debate at the end of life is based on the concept of futility. This concept has had a bad reputation. First, the concept of futility and the full understanding of futility is important. Most medical personnel see futility, not as rationing, but as a treatment plan for their patient. There is a fine line of treatment and knowingly killing a patient. There is a possibility of a slippery slope, but if futility is understood, educated, and produced ethically then the treatment of futility could succeed as a treatment plan rather than ending a life. Medicine has always pushed the limits. Technology has become so advanced that life can now be prolonged even when all else has failed. These boundaries have been breached and the decisions made to

withstand death may not be part of the new goals of medicine. Care was and still is exacerbated to an extent. Care must be given to patients in need, but not abused. Patients do have expiration dates, everyone will die. The can do everything attitude is evolving into the movement of there is a point to stop care. The new goal in medicine pertains solely to the patient and their end of life goals.

III.a.i. Understanding Futility:

Medicine, science, and technology has become so advanced that life itself can be prolonged even if organs within the system fail us. The prevention of death has now become an option to family and loved ones left behind. This improvement in technology allows life to be prolonged even in the direst instances which gives medicine the power to intervene death.[78] Medicine has this power to play a role of God. This power can be destructible and can be harming to the patient. Medicine can be harmful. It can prolong a life that may not be able to exist any longer on its own.

A patient is dehumanized and therefore is denounced of their dignity and respect.[79] Patient's that have gone through treatments to only in the future end up in a "vegetative state" is completely unacceptable when the option of futility allows the agonizing process to stop or to be stopped once it has begun. The term vegetative state is a demeaning and condescending word to place on a human life. Vegetative state literally comes from the word vegetable which implies a shriveled up or limp noodle so to speak. This language has a demeaning connotation and describe the state in which the person lies has no thought or sensation, but the body is able to grow and develop.[80] This means that the child could be in a vegetative state from infancy and grow to become an adult, but would have no interaction or sensation of any other human being. This one word can mean a lot more than just the definition to family and loved ones. The

connotation and language of the word can be offensive and degrading, sometimes even harmful.[81]

Language can be a deafening problem. Talking with loved ones about the child's futile care is based solely on the language, connotation of words, and sympathy used in one's own voice. The language during this time of need and non-understanding is important, and physicians should try to use the words "prolonged unawareness" or "post coma unawareness".[82] The language is a reality building instrument to either warn the family of potential loss or to prep the family for potential gains. The language used initially will set the tone for the rest of the futility conversation.

These resources used to prolong the expected death are not without a price. This is not pertaining to just the actual cost of prolonging life, but also pertains to the emotional, physical, and value of the person's life. Their respect and dignity are also of concern when dying. In this world, unlimited resources are exponential, but rationing is inevitable.[83] Rationing is futility's negative advocate. Futility does not progress because of many reasons, but rationing is always the biggest obstacle to overcome. Rationing is the affect to conserve supplies at a controlled rate. In the medical arena rationing at the end of life, or futility, as some think it is, is the rate at which the physician decides to end a life due to cost to the hospital. Futility, however, is not rationing. Futility is the diagnosis of a medical condition that is incurable, and death is expected to occur within a short amount of time which aggressive treatment cannot cure.[84] Treatment no matter how aggressive or experimental will not do any good to the patient deemed futile. Like any procedure, the good must outweigh the cons. The patient's benefits should outweigh the risks of aggressive treatment. Futility is to provide treatment of comfort, respect, and care. This is when all medical interventions are likely to fail, futile treatment is necessary for the patient

who has suffered long enough. Futility should also be distanced from impossible, implausible, and unlikely because it has already surpassed these attempts.[85] There may still be hope for the patient through the family's eyes, but medicine has ultimately deemed these treatments futile and the prognosis is grim.

Participants in this role of defining futility or the role of accepting futility is ill defined. Physicians and ethicists have this task set before them to find out where the line is drawn to deem a treatment or the child's care futile. This is putting pressure on ethicists and physicians to extrapolate basically a chart saying at what point treatment is futile. The problem with this is, every case is different, and no case will ever be exactly the same. Futility is based on the purely factual diagnosis, but also wavers when judgement call of the physician deeming the expected benefits do not outweigh the negative consequences or well-being of the patient.[86] The attainable goals of treatment may have not been reached and therefore the downward spiral into risk and benefit calculations begin. The medical and ethical justifications of futility emotional and institutional barriers because futile treatment at the end of life causes these defense mechanisms especially in pediatric medicine. If allowing a child to die was that easy, then there is something clearly wrong. The discussion of futility would be considered black and white which clearly it is not nor ever will be. Advocacy by the physician must be for their patient and their individual ethical duty to ensure their wishes and advocate in their best interests.[87] The patient is still the sole responsibility of the physician. The physician should advocate and make sure that no matter which route they choose, the patient should be respected, dignified, and cared for just as a child that was coming in for a checkup. Care of the child does not change because their treatment is deemed futile. Medicine and technology may change during the course of the child's stay, but the respect and advocacy in the patient's best interests should never change.

Futility at the end of life rests on the physician and patient relationship. Futility is easier to talk about with the child or family when a strong bond is formed during the first initiation visit. Most relationships never evolve or in most instances never occur because palliative care and ethicists are not involved until the time of death. The goals of care need to be pronounced at the beginning of the conversations at the time of the new diagnosis pertaining to end of life prognosis.[88] This way the goals of care are stated at the time of the initial conversation rather than during a more emotional trying time down the road. The initial conversation allows the physician to pick up on values, wants, and goals for the patient's treatment plan with logical pathways to help the patient achieve their best benefits in life.[89] This conversation, especially in a neonatal unit requires the parents and family to ascertain the patient's best wishes by considering if they were able to speak, what would they want. The parents are made surrogate decision makers because they are supposed to as parents have their child's best interest at heart. Their decisions forward in care should represent what is best for their child. The child is a vulnerable human being and the physician needs to be trusting in these types of situations in order to pursue the patient's best interests and help the parents understand their best available options to make an informed decision.[90]

Physicians are not able to see the future, even though we would like to think they can. Physicians can predict and recommend certain treatments or procedures to help the prognosis of an individual child's case. These recommendations are only based on their own personal knowledge, and previous facts of cases such as the current case they are working on. These recommendations should be discussed in simple non-medical language so the parents can understand the information provided.[91] The recommendations being offered may also only be the options the physician is willing to commit too at the stages of end of life. The Hippocratic

tradition allows physicians to choose which treatments they offer and which should be withheld.[92] In such instances that a physician would deem a treatment futile, then the scope of the treatment goes beyond their comfort and prolongs their dying while ignoring their quality of life standard.[93]

All aspects of the child's life needs to be thought of at the end of their life including the quality of life they are living in a neonatal intensive care unit. This child, just like an adult, does not want to suffer through death. Most physicians and other medical staff participants agree that there are many differing opinions on treatment success and whether the likelihood of treatment should be offered.[94] The team of physicians and medical staff need to have sufficient communication between each other. The team should agree upon futile or non-futile treatment because having differing opinions can be rough for the family to endure. The claim of futility rests on personal medical judgement which a physician cannot determine the absolute time of a patient's death, but acknowledges that certain medication cannot reverse the trend of descending fate.[95]

Parents and physicians must work together in order to decide the best scenarios for the child patient. In order to do so, once again, the physician patient relationship, or family physician relationship is important from the start of the medical consultation. No matter how small or incompetent the patient is, it is the duty of the physician and medical team to put the patient's best interest forward and allowing the patient to die with dignity. The patient or family is able to control the time of death, and the process of death at the end of life which is non-humiliating and perceived with dignity.[96] The family and medical team can ensure a comfortable death, and allow the pain and burden of hope to be lifted from the loved ones. The patient is able to concede to their death, but allowed their quality of life without being punished through on-

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going medical interventions. Futility can allow peace, it can also provide a pathway to the goals of what medicine really is. Medicine helps and comforts life, but only provides comfort in death.

III.a.iii. Do everything attitude:

Physicians are taught to preserve life. Life is of value and they are trained medically to ensure their patients to the best of their knowledge stay alive. Physicians are the medical professionals to enforce life. Death is unbecoming and unyielding. It takes from humans what they may have not asked for yet. The attitudes of physicians see it as such and try to under extraordinary measures keep their patient alive. Medical technology can heal patients, but it can also do harm.[97] This is difficult in pediatrics. A person can live a fulfilling life and die at what most of society sees as an appropriate age, however, in pediatrics, no age is appropriate to society. They are just children. Medical professions are taught to treat until death parts the living, but the new age of medicine provokes the attitude of quality of life even to a child is important.[98] The physician should not extend life to a child if the situation warrants no intervention. The Hippocratic Oath never states that a physician must pursue interventions where there are more burdens and risks than benefits.[99]

The guidelines of physicians to practice medicine do not state that a child must be kept on life support, ventilated, fed by tubes, or hydrated by tubes. The tradition only evokes values that a physician is too look out for the best interests of the patient. Physicians are not required to prolong the dying process by implementing futile treatments.[100] The physician is not to make recommendations because they feel they are obligated to by their oath to medicine, because the oath to medicine does not obligate them to offer unnecessary treatments. Most medical staff have more of a battle between their own personal beliefs and their own personal ethical dilemmas. Much of the medical personal have not been educated on the ethical situations they encounter on a daily basis. Medical teams are often scared to stop treating children because they

are a vulnerable population.[101] This can become ethically wrong. Yes, children are vulnerable, but same as adults, they are humans that want a dignified quality of life. Physicians need to be able to say no to treatment options or not offer interventions that will not help the child's medical situation. Medical treatment ethically can be stopped and being reluctant can sometimes make matters worse. Being ethically educated or having an ethicist team will help in these situations of futility at the end of life.

Many religions also accept death. Death was never to be non-accepted, and it has changed over the years. Physicians are taught to preserve life at all costs and that life must be of the utmost importance. Religion does allow a gateway to death, and to perceive death as inevitable. Christians believe that death should occur if it is an end to suffering because suffering can also occur after death of the physical body.[102] This entails that suffering does not only happen here in mere mortal instances, but can also occur in the unknown after death. The physician then is only helping the person not suffer in their physical form. They are putting an end to their suffering here on earth. God never intended physical pain or suffering to humans, but since then, there has been a separation from God. Most moral human beings do not want to see another suffer and in those instances the physician then has the duty to their patient to not allow suffering to continue.

Judaism sees that upon death, a person should not be touched in order to allow death to happen on its own.[103] Death may come to the person, but God will only take the child if it is time. Most of the time, at the end of life, families and loved ones have the issue of hope. Hope is considered an issue because it may become more of a burden than a helping hand. Hope should prosper, however, people must understand that sometimes hope isn't enough in futile cases. Miracles do occur, they are divine, and ever so scarce, but hope can lead to devastating

hard terms. Physicians must re-examine their fears because dying does not need to be prolonged because there are no requirements by medicine nor religion.[104]

III.a.iv. Care has an expiration:

Medicine can achieve some miracles. Sometimes medical professionals do not know why things happen. If medicine can achieve these miracles, then it is hard to withhold these life sustaining treatments and it is even harder to take someone off of these treatments.[105] Treatments should not be suggested if deemed futile. Once, parents or loved ones choose to put their child on life sustaining treatment, it is so much harder to try and wean them off of life support. That is when hope and miracles play a larger role in end of life cases which makes it harder for the medical team to induce futility into the conversation. Ethically speaking, it is the justification of treatment being offered not the withdrawing or withholding of treatment.[106] The intervention being offered to the patient's family needs to be justified because the withdrawing or withholding of treatment is justified by double effect, value ethics, and futility. Physicians are burdened by their choices. In certain situations, physicians have acted against their conscience when providing care to their patients.[107] If a physician sees that their morals and ethics are being compromised then ethicists involved should review the case so that coercion of medical interventions do not take place. Parental authority is granted a great precedence in decision making, but when treatment seems too great and benefits to uncertain, they are mere players in a team effort [108]

Teams can fail, even in healthcare. Physicians and other medical staff may have differing opinions of care. This can cause grave turmoil during withholding and withdrawing life sustaining treatment which leads to prolongation of the dying process.[109] These feuds between the medical team can cause burdens on the family. The decision process needs to be smooth

with unison and excellent communication. Many physicians are conscious of pain awareness in neonatal children. Their pain may not be suggested or discussed with the individual child, but there is a scale to which the physician can adequately provide proper doses of medication. Physicians may however, give inadequate doses of pain medication because of the fear of hastening the child's death.[110] The physician is not able to give adequate pain medication because of fear of the patient dying. This makes the child suffer and endure pain for long regimes of time. Offering other treatments to patients and their families does not help the issue of inappropriate pain medications. The treatments that are offered may be more of a burden.[111] The child is already suffering from pain, and then to add futile treatments would be cruel. Most medical personnel see that they do not give up on children soon enough.[112]

Medical teams may go to long without looking at the bigger picture. This neonate is a small tiny child that has been poked and prodded ever since it came into the world. There is a point that one must reach to say stop. Most medical teams see this factor too late. Every time a decision is made, it must be ethically justified and the physician is then responsible for their decision.[113] If the physician sees to prolong life then they are to justify their reasoning. The switch in medicine is to justify the actions of not doing anything. There is a point at which care ends, and death takes over. Care will always be important in the dying process. Rescue mode by providers and other medical staff does not always need to exist.[114] Maybe, rescuing the child has changed in definition at the end of life in futile care. A rescue is when the physician and family come to terms with their ailing child to discontinue care and make their beloved child comfortable, happy, and at peace with their coming death. Rescue does not always mean treat, it could mean to let go.

This section will discuss the four principle approach with Catholic and Islamic customs, the patient-physician relationship at the end of life, and symptom management at the end of life. These topics will be discussed further in more detail.

III.b.i. Four Principle Approach with Catholic Customs:

The first principle to compare is autonomy. Autonomy is perceived as the patient's will to choose what is best for themselves in a given medical situation at the end of their life. If not able to speak for themselves, their family should act in accordance to the patient's known wishes and values to sustain their autonomy through the surrogate decision maker. In Catholicism, all people have the right to decline medical treatment even the right to life sustaining treatment, and also the right to stop treatment once it has already started.[115]

Symptom management at the end of life could include nutrition, pain treatments, sedation, or other symptom alleviation. In Catholicism, the patient should be able to identify the risks and benefits of the situation in order to give a free and informed consent based upon the capacity of the patient to accept such treatment options or refuse them.[116] Patients are able to freely decide at the end of life what management options they would prefer and what options they will decline. The third pillar and staple in Catholicism is the right to autonomy, privacy, and liberty during the end of life in a person's medical care.[117]

The second principle of beneficence is quite important in Catholicism. This act is "doing good" by the patient. This is also considered the best interest standard. The physician may see that certain pain management, or nutritional needs are the most effective routes of care, and eases the patient's suffering at the end of life. This paternalism and beneficence by the physician coincides with the patient's autonomy to have the right to refuse treatment and should not supersede that right, but rather work side by side to better serve the patient's interests.[118] The

offering of such treatments like pain medication or nutrition at the end of life may have reasonable benefit to the patient without any ramifications or direct harm to the patient. This can be considered ordinary means that the physician offers which is meant to be treatments that will benefit the patient without a lot of burden.[119]

The third principle of non-maleficence coincides with the principle of beneficence. Non-maleficence is "do no harm by the patient". In this case, the physician should not offer any treatments that do harm by the patient nor should they do anything if they do not benefit the patient based upon their values and wishes at the end of life. When the treatment option for symptom management does not cause great harm, but the overall benefit is only slightly above nonexistent then the option should be rejected.[120] This would be an extraordinary need and the catholic tradition expresses the distinction that not all life needs to be prolonged based upon the do no harm principle.[121]

The final principle of justice also plays a vital role in Catholicism at the end of life. There is a difference between allowing one to die versus killing a patient.[122] The patient may request pain medication and deny nutrition for their symptoms. In this case, the patient may actually hasten their death by taking more pain medication to control their symptoms yet by denying themselves food and water that also will hasten their death with malnutrition. The physician then gives the patient their right to decide and acts on behalf of their will to act fairly by performing the wishes of their patient which may be in fact their right to die. The act of relieving pain, and acting in accordance with the patient's wishes is morally right and legally acceptable.[123]

III.b.ii. Four Principle Approach with Islamic Customs:

Autonomy, again as the first principal, in Islam is not as prevalent as it is in Catholicism. It takes a back seat to other principles. Islam ethics and culture drive paternalistic care and

dominate the scope of authority where in western culture autonomy is far more important, but in this case of Islam, autonomy is far from being recognized as a standardized principle.[124] This principle is seen to interfere with suffering at the end of life which is seen as a test from God for the believer or a form of punishment.[125] If a person can take pain medications to not feel pain at the end of life, then they are not adhering to God's will of either a test of faith or their punishment of wrongful deeds. The physician knows what pain medications and doses are acceptable in the patient's situation. The use of pain medications to relieve pain is allowed under certain circumstances that will be discussed later. Life is meant to be sacred and that preservation overrides all other rights as well as the right to autonomy.[126]

The second principle of beneficence insists that the physician does right by the patient. The Islamic ethics principles that drive medical care circle around the rule of no harm no harassment that solve most ethical issues in care.[127] The physician's duties are to treat the patient, and in turn the patient is unharmed and is treated with a high quality of care. There shall be no harming or intentional injuring of another man and in the event that a patient is harmed, or does not benefit in their medical situation, then it should be immediately stopped.[128] The benefit is to the patient and the physician is obligated to treat. God does not wish harm to his humans, not from him and not from other human beings, they should strive to do their best, not to harm others.[129]

This also coincides with the ethics third principle of non-maleficence in doing no harm. Islam sees that most resolutions to ethical dilemmas is to error on the side of caution that best benefits the patient and does as minimal harm possible for the best possible outcomes. This way the physician can use their medical knowledge and error in the best interests of the patient. If a medication or treatment is proven to be harmful then the physician should ensure that the patient

not take said medication or treatment even if beneficial because there shall be no harming of one man to another.[130]

Justice plays a minor role in Islamic ethics as the concern is based on the individual patient rather than the community or global atmosphere as a whole.[131] This final principle in Islam is not a strong principle because Islam ethics focuses their abilities towards the individualized patient and not the public good. The patient themselves is the main priority not all the justices that come with the population as a whole. The Imams will restore peace and justice when it is necessary, but in the meantime it is not for the layman person at hand.[132]

III.b.iii. The Patient-Physician Relationship at the End of Life:

Ninety-six percent of patients believe in a higher power of some faith based religious beliefs in the United States, and most present day physicians do not see religion as part of their medical care.[133] The patient as a whole should be thought of as a learning process for the physician as well. The patient is not just a dis-functioning set of organs, they have a background and a set of values that they came from to determine their course of care they so desire. The physician may be the teacher of medical knowledge, but they are also the student as the patient describes their preferences in care. By learning more information from the patient and family, the physician can drive quality care that inspires patient values to drive care that optimizes communication and enhances the patient-physician relationship.[134]

Once in a lifetime does death occur. This means that patients, families, children, or friends only experience this one time in their own life. They also only experience it once if it is their mom or their dad, or even a sibling. Understanding that the patient or family member sitting in that hospital room or bed is experiencing this for the first time is where the patient-physician relationship begins. The goal should be to be a part of something bigger than just seen

as the unseen physician in the white coat. Almost all patients rather have their physician discuss with them or acknowledge that spirituality or religion is a part of end of life care and would like that topic to be respectfully discussed or communicated effectively throughout the medical care.[135] Optimizing care and improving care satisfaction will improve quality care at the end of life and the physician can be a part of their journey.[136]

In the Catholic tradition, the physician may have more power or sway than a regular physician, and may become too paternalistic but that may allow the patient to lose sight of their own autonomous decisions.[137] Patient's look up to their physician for their opinions and medical knowledge to lead them in the most obtainable goals in their care. However, physicians may overstep and lead patient's to accepting treatment that might not align with their religious needs. The physician is looking out for the patient's best interests, but the patient's values may differ from the end goal in mind. This is where ethical conflicts can arise when religion and medicine are intertwined. Strong religious beliefs could add ease to the dying process if they are well established early on in the patient-physician relationship.[138]

It is always easier to communicate whether a patient's prognosis is good or poor so that the patient has time to prepare for death if it is inevitable.[139] Physician's should always communicate well with their patient's prognosis so that they have time to absorb the information given to them.   Truth telling should meet three principles in Catholic theology: the truth is essential to the patient's preparation for death; the truth is dependent on the physician-patient relationship, and when the truth is given to the patient it must be done slowly and poetically to preserve hope in faith of God.[140] The truth should only be concealed from the patient if it would cause direct pain or suffering to the patient because more harm is done when the desertion of hope no longer exists.[141]

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The physician in Islam tradition could be a part of the "suffering" process that the devout travel through during their stages at the end of life. Suffering is a two-fold process in the Islamic religion at the end of life. There are two purposes of suffering imposed on humans during the dying process: the first being a form of punishment that extracts sin and the second being a test of their soul to reinforce their spiritual status.[142] God will punish the people that have sinned, and have chosen wrongly in their life. Then he will test their soul to determine their spiritual status for the hereafter. When the body dies, the suffering is complete, and God has chosen where the soul travels to in the hereafter. The need to understand this journey a human makes while suffering and the discoveries craved to overcome that suffering is what makes Islam and medicine embark on a work together to understand the moment of suffering and death.[143]

The Qur'an, the Tradition, and Sharia law see that humans of sound mind and spirit can make their own autonomous decisions knowing one is good and one is evil.[144] God has given life to mankind and has set forth religious texts and proverbs to lead a righteous life, but mankind also has the choice to choose evil. Based upon a person's life decisions, they have decided individually what is right and wrong and upon the dying process they are examined by God who will judge the actions a person has chosen which is morally or ethically justified proceeding to the hereafter.[145] The act of suffering is defined in various texts in the Qur'an and notes that only God can begin and end the suffering because all of God's acts are purposeful.[146] Even though one may suffer at the end of life, it is not seen as suffering but repenting their sins, or becoming closer to God by his trials and tribulations posed before the dying person. God alone controls the dying process, and the sins expelled by suffering will offer some redemption for the afterlife.[147] The physician treats the medical needs, and understands and abides by the patient's religious needs and together they can navigate care at the end of life. Suffering is treated as the divine

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plan for all humanity because when it occurs, it educates and disciplines the person to affirm to the submission to the will of God.[148]

The physician and medical team work together to determine therapy that is beneficent and in the best interests of the patient and will refuse harmful requests of treatment to the patient.[149] In Islam, physicians must act beneficently towards their patient and use their own medical judgment to deem a treatment plan necessary or unnecessary. Lastly, the physician should work with their patient, family members, hospice teams, palliative care, or other medical members for solid communication to decrease the possibility of conflicts.[150] This way, the physician and medical team can use the Islam faith and be guided by patient values after the patient passes which may include: a grieving process, an Imam present, the washing of the body, prayer, or burial arrangements which are all very sacred and an integral part of the dying and after death process to the religion of Islam.[151] Educating medical staff on the Islam religion is important, but it is also important to have a personal relationship with the patient so that they themselves can address their personal belief system, and promote their own free will and autonomous thinking in their own medical care.[152]

III.b.iv. Symptom Management at the End of Life:

Palliative care is the support of treatment aimed at relieving pain and suffering rather than sustaining the patient's life; it focuses on symptom management.[153] This group of physicians' focus on supportive care and comfort at the end of life. In Catholicism, this is acceptable and wanted to relieve unwanted symptoms that do not coincide with the patient's values and goals at the end of their life. This could lead to discussions of CPR orders, or feeding tube placements, or aggressive or non-aggressive treatment options all pertaining to and surrounding the patient's wishes for their medical care.[154]

The support of Palliative Care at the end of life is an important piece that honors patient's values and wants during the dying process. Palliative Care focuses on the symptoms during a patient's care. During the end of life, Palliative medicine can determine more closely in this specialty what a patient needs to be comfortable, pain free, and symptom free during their last days. Catholicism chooses to use this concept to alleviate pain even though it may lead to a shorter death, which will be explained next in the concept of the double effect. Palliative care surrounds itself with the patient's intractable suffering, and focuses on alleviating their symptoms for better management.[155]

In Islam, they respect autonomy to a certain degree, but do not agree with suicide or ending one's life by euthanasia or physician assisted suicide.[156] It is not ok to ask to die, however, it is ok to be allowed to die because ultimately God chooses that time and place. Palliative care physicians can use their expertise to provide symptom management to their patient, however, at the same time God is in control whether the patient is healed or not.[157]

The ethical dilemma essentially does not exist in Islam with symptom control by palliative care. Pain and other symptoms are managed by specialized physicians and God alone is the only one to cure or take life.[158] Physicians are seen to be beneficent and act in accordance to their patient's needs and wishes. They provide care that their patient expects. A physician will be held accountable on their own Day of Judgment before God, and then their own actions will be acknowledged as right or wrong.[159] If the patient sits in pain and suffers without the physician treating the symptoms then the physician causes harm which does not escape their responsibility to the patient and God of their oath of no harm no harassment.[160] Therefore, symptom management is as important to the patient and to the physician. The palliative

physician will assess the patient's needs, act accordingly, and let nature take its course as both believe in God and what He has in store for each of them.[161]

In the Catholic tradition, sometimes it is morally right to allow a person to die.[162] A patient may forgo treatment of extraordinary means or may unintentionally hasten their death. By forgoing life sustaining medical interventions, a patient may experience unsolicited pain in their dying process. This pain can be alleviated by calculated pain medication to benefit comfort to the patient which outweighs the possibility of an earlier death.[163]

Most families are nervous about withdrawing or withholding treatments or the use of pain relief because it may in fact hasten the patient's death.[164] The double effect uses the benefits of the patient outweighs the harms so the treatment option of pain medication even though hastening death is morally acceptable because the benefits outweigh the harms. The physician is treating the pain and suffering of the patient and the aims are relief not death of the patient that may co-exist within helping the patient relieve their pain.[165]

Not allowing a patient to die would hurt the patient and family possibly more, and violates the patient's own personal justice since there exists no benefit from further treatment. There is a desire for pain medication to alleviate the pain as one approaches death which also allows for the family to find closure since it is known the end is near but their loved one is not in pain.[166] The double effect pursues the patient's wishes and allows the patient to die with the intent of alleviating a patient's pain and suffering. If the four conditions of the double effect are met by: the act is not morally wrong, the bad effect does not cause the good effect, the physician must not intend the bad effect, and the bad harm may not outweigh the good harm then the act is morally and ethically permissible.[167]

Islam does not use the term double effect, but they see pain management as a necessary means at the end of life. There is an obligation to alleviate unnecessary pain at the end of life whether God has a test, trial or redemptive sins that the patient may have to endure, but undue suffering is not intended.[168] If the patient has significant pain they may ask for pain medication and it should be given. In this case, if the pain medication leads to an earlier death, this was not the intended event and is morally acceptable. What is important is that the patient is free from pain and is comfortable in that moment and because everything is determined by God, if life is shortened it was because God determined it not the physicians.[169]

In Islam, the double effect is not the most important concept, because God determines the end and not the physician. So in this case, if the medications are given to relieve pain, then this is acceptable and God then will determine when the patient dies, not the medication itself. The act in itself of giving pain medication is an act of good, or beneficence towards their patient, and that is driven by God because there are choices between good and evil and physicians should morally choose the act of good and do no harm for their patient.[170]

In Catholicism, all life is seen as an intrinsic value. However, when a person's life has more burdens than benefits to enjoy their life, then treatments may be forgone because life in itself holds no value.[171] Quality of life to every individual is different, but the most common aspect of this concept is that when burden outweighs the benefit then it is not necessary to continue on the path of burden and harm. The level of living is such that the patient cannot carry on with their life in a meaningful way.[172]

Quality of life attends to the patient in a larger sense than just a disease or a medical anomaly.[173] Insisting on treatment in all cases may not be the most attainable outcome. A patient's values may rest in a higher purpose because life may not be worth living if it doesn't

produce the purpose of the individual's goals any longer. The withdrawal of life-sustaining treatment made by an alert and an oriented adult individual should always be respected and complied with unless contrary to the Catholic moral teachings.[174]

In the event that the patient cannot speak for themselves the surrogate decision maker and the physicians should take into account the patient's known wishes, and the medical prognosis using the best interest standards to justify an interpretation of what the patient would have wanted.[175] The patient whether lucid or not should have the authority to make their own medical decisions either by themselves or through their own values expressed by a family member. Autonomy and quality of life go hand in hand, and the use of a patient's autonomy to decide their end of life care is based upon the quality of life they have left and their religious decision with God. If we do not observe the right of the individual's quality of life's increased suffering to forgo medical treatment, then we are personally attacking a patient's autonomy and free will to choose their course of care.[176]

The Islamic perspective sees quality of life as one of the most important principles or concepts in the Islam religion. However, they see that no Imam or person can judge the quality of life of another person because all life is inherently of intrinsic value.[177] Even though quality of life is important, no single person can judge the individual's quality of life from their own perspective. Sanctity of life is paramount because every person's life should be preserved and it is only in some instances when life can be morally shortened and justified.[178]

One can only take life for a just cause, and then meet judgment to liberate the soul from the body.[179] In this stage of life, the patient's quality of life should not go through unending suffering because ultimately the goal is to have their soul liberated from their body and moved on into the next life chosen by God himself. The patient may ask for symptom control and pain

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management at the end of life which would provide a higher quality of life that is essentially a comfortable life.[180]

Some sects of Islam see that any prolongation of life by mechanical means that support no benefit to the patient and no known quality of life would be strongly disapproved.[181] Even though a religious Imam or other religious figure cannot identify a person's quality of life, there is an identifiable measure of what a reasonable quality of life can be for a person and a physician in their expertise which would be able to justify their assumptions. If all standard treatments have failed, and there are no further alternatives, then the patient or family should progress in a primarily palliative and comfort approach to preserve the quality of life and dignified death of the patient.[182]

IV. Conclusion:

These topics ascertain that informed consent in pediatric medicine have very heavy dynamics. Informed consent in pediatrics does not just deal with the relationship of patient and physician. This relationship is a social construct that includes patient, physician, and parents. This construct gives ethically informed consent to the parents, but allows power for parents to overrule their child's assent. The problem of informed consent in pediatrics is that there is no known factor of telling whether a child can fully acknowledge, understand, and develop the information given to them in order to make a proper informed decision about their care. The interesting factor here is that ethics is a discussion, a debate for a matter of fact, of whether something is ethical or not. Informed consent has been stated ethically if done correctly and is truly and utterly informed consent. Assent has not been morally established as a legal ability for a child to make. The justification of assent in pediatrics is the fact that it is informed consent; the child is ascertaining their right to their autonomous decision; the physician acts beneficently as

their duty is to their patient and uses their best interests at hand, and lastly above all else, does not need science to define a certain age that a child can make a decision. Quality ethics consultations can help drive decision making and consensus amongst the medical providers, patient and family.

Futility at the end of life in neonatology does not allow for much objective circumstances. A lot is based upon subjective interpretations of parents and their love for their child. Complications at the end of life exist. Physicians have changed their attitudes from a "do everything possible to treat the patient" to an attitude that "care may have an expiration time". Futility has been seen as a possible solution to pain and suffering for the child patient. Death in pediatrics, especially in neonatology, is among the worst deaths imaginable because it is taking a life away from a new born child. No one wants to see this occur, but it is the duty of physicians and research to better understand futility in these complicated situations to bring forth ethical standards to feel at ease with one's decisions. Futility can be a decision at the end of life, and it may be the ethical standard during a time of dismay. Futility can bring peace at the end of life for someone who can't decide it on their own. Ethics consultants can help drive consensus in difficult decision making during end of life challenges.

Medical ethics consultants, physicians, nurses, other specialties and medical providers first and foremost should communicate effectively with their patients upon admission whether they spiritually or religiously affiliate with a type of faith. It is important for the medical team to acknowledge faith at the end of life, and especially during symptom control at the end of life. Islam or Catholicism may each view end of life symptom management differently depending on the situation at hand, or they may each use different texts or religious prophets that determines the course of action at hand. However, both religions may at the same time agree with the same

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outcome, but have different ethical principles that guide the management at the end of life. No matter what religion the patient associates with, the patient if conscious should use their autonomous decision to direct their care by their religious beliefs. Ethics consultants should be able to coordinate care between the patient's religion and contemporary ethics framework. They may use other resources such as pastoral care, spiritual care services, a priest, or an Imam to help manage the ethics conflict at hand with the coordination of the patient's religion in ethics framework. This way, care is directed by religion and ethics in the patient's best interests and values that ultimately acquire patient quality care at the end of their life.

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Chapter 4: Ethics Consultation Quality in the Organizational Setting of Pediatric Medicine:

Organizational ethics provides a healthcare system a way to act morally throughout their entire organization. This structure provides an ethical understanding from the top down. In pediatrics, this structure involves more complications because there are more clinical, patient safety and conflict of interest issues when dealing with children. The child's best interests are discussed by healthcare personal and parents rather than their children speaking for themselves, whereas in adult care, patients can ultimately speak for themselves, legally, and competently.

Organizational ethics is the backbone to deciphering ethical dilemmas in pediatrics which will require ethics consultations to solve the problems that arise in pediatric healthcare organizations. Organization and clinical ethics will be more clearly understood by defining and understanding organizational culture. Organizational ethics is the groundwork for fixing the dilemmas in conflicts of interest, quality and patient safety. Pediatric ethics consultations will be able to properly decipher the ethical dilemmas in these areas to ensure an organizational ethics plan to be carried out for the best interests of the patient.

The second half of this paper focuses on child maltreatment. Child maltreatment unfortunately is still an apparent issue around the world. Maltreatment comes in many forms including but not limited to: neglect, physical, mental, or emotional abuse, or malnutrition. Of course there is an ethical and moral standard against any child maltreatment, however, the physician's and medical staff members' roles in these cases require a balance between their beneficence for the child versus justice for the child and their misfortune.

The ethical balance between non-maleficence and justice in child maltreatment situations are dictated by the role of medical providers, the organizations responsibilities, and the ethical framework's obligation to manage child maltreatment situations to provide high standards in care and lower moral distress for all parties involved. This will be shown by defining non-

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maleficence and justice in the context of child maltreatment thus leading the role of medical staff as to whether to stay in their role as a clinical provider or fight for justice of their patient when facing these complicated scenarios. Professional and organizational duties are then defined to help with role conflicts. This way quality healthcare ethics can manage conflicts of interest and help align goals for clinical providers for the future care of children who have been mistreated and brought to the attention of healthcare facilities.

II. Organizational Moral Agency & the Culture of Quality:

This section will discuss organizational and clinical ethics, healthcare organizational culture, funding for medical research, and parent conflict with physicians regarding consent and autonomy.

II.A. Organizational Culture:

Organization and clinical ethics are the defining factors of the healthcare organization. The system is based upon their organizational and clinical ethics and how they are integrated into the system in order to produce the best possible care for pediatric patients. The organization's culture and ultimately their moral agency will define the organizations ethics throughout the process of care.

II.a.ii. Organizational and Clinical Ethics Defined:

Healthcare organizations stand for many different missions. Each organization has particular goals, values, and vision. These concepts are applied to organizational ethics. Organizational ethics is explained by the reliable values and the moral points that the organization applies internally and externally throughout their system.[1] Organizational ethics should permeate the organizational structure of the company. These ethical values and morals should go beyond the mission of the organization; these concepts should thrive throughout every

decision, action and problem. There are three main parts of organizational ethics that should be the moral compass of the company. These three parts are: incorporate the mission, values and vision; have the capability to do the right thing and execute the plan and have finesse in identifying ethical challenges.[2]

Organizations make choices every day. The choices they make need to be addressed ethically and in a way that their employees follow morally so the external participants understand the actions of the company.[3] Each member of the health care organization has a specific role and demeanor they are supposed to follow by the guidelines its organization sets. The role of each employee plays a particular part in that accountability of the ethical values and mission of the organization.[4] Since an organization acts as a whole and is not individually scrutinized for the problems that may arise, the organization's moral agent or the way the organization makes decisions will be the key role when problem solving. The obligations of the health care organization are to ethically respond and systematically evaluate their internal climate in order to assume their role and responsibility of the ethical demeanor of the company and portray their values when considering the practical choice when problem solving internally and externally.[5]

The efforts to define themselves as an ethical, valued, vision-forward health care organization are based on their organizational setup and the way they solve institutional problems. The company's organizational ethics, if set up correctly by proper internal structure of ethical procedures, should develop a proper organizational moral agent to determine ethical solutions to problems that arise. The organizational structure is crucial to survival.[6] The efforts of the organization will define the values of properly solving ethical issues that arise in the future. There may even be nothing spoken of the actual word "ethics", but the values that

permeate throughout the health care organization is a standard of organizational ethics without using the actual phrase.[7]

The patient is the focus in healthcare. Clinical ethics focuses on the patient and makes sure that from the time the patient is admitted to the time the patient is discharged, the stay of the patient is ethically justified. Clinical ethics concentrates on the clinical practices at the bedside.[8] Clinical ethics deals with different concepts of ethics. The concepts of autonomy, beneficence and non-maleficence are the standards of clinical ethics and patient care. The institutional ethics committees analyze the policies of patient's rights and protects the patient's autonomy during any clinical situation.[9] Different committees and review boards have been developed in order for patient care to be handled ethically.

However, clinical ethics could be a disguise as professional ethics where the physician has the ultimate power to make the decision. Physician power can be considered an organizational problem.[10] This problem of clinical ethics focuses on the patient, but the physician can veto those opinions and suggestions of the patient any time. The blockades to protect patients and to secure their well-being is the involvement of clinical ethics, but if the physician has the ultimate decision in the matter then the organizational structure of clinical ethics is a problem. Many ethical problems have organizational causes such as physicians taking control of the clinical arena instead of involving a medical team setting which would integrate clinical ethics instead of standard professional ethics.[11] The physician is a key role in any clinical experience. The physician however, should not be the prime factor during a patient's clinical experience. The mission of the healthcare organization and the physician should be a common goal. The ideal clinical ethics should encompass the mission statement of the organization and the employees of the company. Most of the time clinical ethics committees are

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not able to address organizational ethic issues even though clinical ethics takes on the mission of the organization.[12]

II.a.ii. Healthcare Organizational Culture:

The moral agent of every organization is ascertained by the culture of that specific healthcare system and the way the system is run. Culture of an organization can also be related to the character of the organization. This character, just like an individual's character, relates to the traits of the company. An organization's ethical climate or culture is what that organization's ethical standards and procedures are for its system and how to address the ethical problems and issues that arise.[13] An organization's ethical culture is how an organization's moral agency is defined. Understanding ethical culture as the standards the organization holds for its employees and members involved with the organization allows for ethical debate over the company's moral agent. Moral agency performs an investigation of institutional culture to understand how an organization makes their decisions and whether those decisions have greater benefits, harms or manifests good throughout their interactions with other institutions.[14] The way the system is run is represented and directed by the chain of command. Each role in a healthcare organization has a specific duty to evaluate the demands internally and externally. Reporting employees should be evaluated and held accountable just as their boss is held to the same standard by their supervisor.

This chain of command evaluates the organization's moral agent by the decision making process that should be institutionalized by morals and values in order to evaluate the roles of morality and accountability following decisions made during ethical dilemmas.[15] Most healthcare organizations are judged upon their executions, quality, climate, and patient care. The employees of the organization are responsible for this outcome. This in turn evaluates the chain

of command at a closer microscopic level. As an organization, individuals are responsible for their actions.[16] An organization can be considered moral agents in the sense that like individuals, organizations can be morally accountable. However organizations do not in the literal sense make choices or actions; only individuals have the authority to do so. Individuals should judge themselves and their job descriptions based on role morality. Role morality is defined by an organization evaluating the roles of their employees as to whether or not they have carried out and fulfilled those roles.[17] Each person working for their health care organization should not blindly follow the role obligations deemed by their position. There may be unethical role obligations which, when followed, may be perceived negatively and possibly cause an employees removal from their position if the organization is under scrutiny. An individual may be in tough situations which the moral agent of the organization should institutionalize good moral values in order for individuals to base their own values off of in order to produce the same common morality in difficult situations.[18]

Health care organizations set goals, apply standards in order to meet their goals, assess their goals and are therefore judged by their goals. It is not an easy task to develop missions, values and organizational goals. However, if an organization fails to meet the standards of their own mission statement, then their organizational ethical components are flawed. The organization's culture needs to be in line with the values, mission, goals and vision of the company in order to carry out the standards of the company's moral agent.[19] The organization and the people within it have the ultimate power to make either productive or detrimental decisions. The healthcare providers are able to encourage and recognize the culture of the organization in order to exceed patient expectations.[20] It must be the duty of every individual within an organization to individually challenge their own personal moral agent and be in line

with the ethical moral agent of the company. New views and responsibilities of care in health care organizations have changed. An organization's moral agent or in other words the definitive decisions the company makes should support the best ethical practices to invoke their moral worth and to strive for excellence.[21]

II.B. Professional Conflicts in Research:

Conflicts arise in healthcare organizations every day. Conflicts of interest, however, should not occur quite as often. Conflicts of interest continue to exist in medical research, and more so with pediatric research. Funding for medical research can create conflicts of interest between parents, children and research foundations. Conflict may also arise during the explanation of the fully informed consent or the autonomous pediatric structure.

II.b.i. Funding for Medical Research:

Patients and parents rely on the trusting word of the physician or scientists governing medical studies when enrolling their child in medical research.[22] Some studies are not profitable to the patient directly. Some studies benefit the child population for future endeavors in medical research. Parents have the responsibility to rely on the physician's word and trustworthiness of the investigators that recruit their children in order to ultimately enroll the child in their specific research study.[23]

Many researchers base their research on no benefit higher hazard pediatric studies. This no benefit means that the research conducted in most pediatric cases are for future children with the disease and not for children being treated with the disease. These studies are a potential risk however for children with no benefit to them directly. The funding aiding these research studies are funding research for the future benefits of children, but not benefiting the family or child of the current participant. The no benefit, higher hazard study should not represent more than a

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minimal risk for children in the study because these studies are advancing knowledge for future pediatric patients.[24]

When this type of medical research study does not benefit the research subjects directly then there is someone that is possibly benefiting from the study, but may be obtaining these results unethically or immorally. There are no requirements in the United States to disclose financial conflicts of interests to patients participating in the study.[25] The Declaration of Helsinki requires disclosure of research funding, but does not require the disclosure of financial conflicts of interest involving researchers, funding agencies, medical centers, and industries to the research subjects or in pediatric cases, to the parents.[26]

Most patients and parents would like to be informed to the fullest extent in order to participate in a research study. If the patient and parents are informed of the financial conflicts of interest in the research studies then they are more willing to participate even though there may in fact be a conflict of interest. For example, the research subject and parents are more inclined to participate in the trial if they are told that the company funding the study is also the company that produces the drug. The importance of being informed in a research study is the fact that participants need to understand the entire operation. If a participant was misinformed or the perceptions of the research study was misconstrued then the participants may not have even participated in the study if more information had been conveyed in the beginning. The research study would be deemed unethical if the information of the research study was not properly produced during the beginning conversations of the medical research study because more parents would participate if notified of all interests of the parties involved.[27]

There are always new and upcoming research studies to which vulnerable parents allow their children to become subjects. Parents may be emotionally vulnerable to because the

research study calls to them as a possible solution and a means to eliminate their own child's suffering from the disease that the scientists are trying to cur[28]e. Researchers prey on the weak in the way that they try to attract parents with children of the disease so that they will be more willing to involve their own child because hopefully this research will produce a treatment or cure. These results are highly unlikely for most research subjects. However, most parents will do anything for their child in order to find a solution to their ailment and in many of these cases they also look to their child's physician for advice. Parents can be very malleable under these circumstances thus are easily persuaded by their child's physician, while remaining unaware of their physician's vested interest in a particular research study. Physicians may have a conflict of interest in recruiting their patients into the research study because of their own potential financial gains.[29] The physician can play an overbearing and paternalistic approach to make parents feel as though they are making the right choice by allowing their child to participate in the medical research study. The physician can also receive kickbacks, bonuses, or relative value units which all correspond to money being paid by the research study to the physician for accessing their patients to enlist in their research studies. Most scientific studies have no accurate information to support their study for present children benefiting in their study. Children in the present studies will more than likely to not benefit from the study, but future children may benefit from the research at a later date. Some research studies are also not safe for children or effective for their current situation. All studies should be listed to only include medical studies that are prevalent to the certain children needing the intended cure or treatment option. Physicians or other recruiters for medical research studies need to be careful and aware of what they are presenting their patients and give options to enter a research study. This process begins with the physician recruiting patients for a study that may not even benefit them directly, and the parents are in a

vulnerable position to have their children recruited, but none of this matters if the study is not approved by ethical review boards.[30]

Physicians, recruiters, researchers, and institutional review boards need to work together in order to create ethical research studies which children can be a part of in a safe environment. Ultimately, conflicts of interest correlate with trust in research studies and the researcher, which if conflict of interest takes place, then the research and research community as a whole is damaged.[31]

II.b.ii. Parent Conflict with Physicians Regarding Consent and Autonomy:

There are certain ages when children can speak and understand different topics for themselves. Infants cannot speak for themselves. Young children may not have the capacity to understand and make the decision for themselves. Adolescents have more of a comprehension of their treatment options and how to decide what is best for them. In most cases parents are the deciding factor and have the responsibility for understanding what is in their child's best interest.[32]

The physician shows their moral agency through the main ethical principles that a physician should always uphold during patient care. Autonomy, beneficence, non-maleficence and justice should always be upheld throughout patient care and the physician should be guided by these values through the process. All healthcare professionals, especially physicians should hold true to morals and values of the organization and of their own personal beliefs. However, these values should be directed at providing the utmost respect of care for the patient. The duty is to the patient, and their knowledge is to inform, suggest and ultimately look out for the best interests of the patient. The physician should be guided by ethical values when dealing with their patient in ethical challenges, and must obtain the care and respect of the child's autonomy and capacity for understanding throughout the process of their stay.[33]

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In pediatrics, informed consent and autonomy is a difficult and complicated subject. Unlike adult care, pediatric patients cannot necessarily speak for themselves or understand the medical terminology to the extent that most adults can when making full and informed medical decisions about their care. In the case that the child cannot decide for themselves, the referred term, lack of capacity, deems the parent as the surrogate decision maker.[34] Conflict of interest between physicians and parents can be quite common. Two different parties deciding what is best for a child who cannot speak for themselves. It is a guessing game that should not be taken lightly. Parents views may differ from the physician's views based on their values and beliefs.[35]

There are many challenges to overcome in pediatric care. Parents and physicians views alone may be differing which make the process of care strenuous to the point of exhaustion. Children who are old enough to understand their medical situation are sometimes harder to treat than children who are dependent on their parents to make decisions.[36]

Children may refuse care and physician's need to balance autonomy and respect their decisions even if parents and their own beliefs don't see it as the proper decision. Children should be given the same respect that adults are given even if they are not able to fully consent or use their own individual autonomy in their medical situation. If the patient is not able to give fully informed consent or desired notion of care, then there should be other avenues to pursue in order to respect their feelings, personal beliefs, and demonstrate the understanding of their wishes. Assigning a patient as a person that does not hold the capacity to make their own informed decision is not a black and white area. A physician needs to decide whether the child comprehends the medical situation in order to properly care for themselves. Parents may want the right to choose for their children no matter if their child understands the complications of their medical situation or not. Physicians may also have a paternalistic hold on the child which

will sway the child's decisions to what the physician sees as the best solution to their problem. Pediatric patient participation will always be a grey area, but physicians, and parents, need to come to an understanding and respect the child's personal beliefs and autonomy, in order for the patients best interests, wants, and needs to play forward.[37]

Moral agency plays the role of the advocate. Parents' beliefs about their child and their best interests versus the physician's medical background and the beliefs of medical science are at war. Parent's values to uphold their religious, moral, and ethical beliefs throughout the process of care for their child are the barriers to success from the physician's standpoint. The parents see medical science and the physicians' own personal beliefs of life and how a parent should treat their child as barriers to their child's needs. In the end, to understand what any child's best interests are, is to first listen and be able to relate to them to see their perspective on life, and if they can't speak for themselves, then there is a middle ground where commitment, compassion, and ethical practice make a decision for the best interest of the patient.[38]

III. Quality & Patient Safety in Pediatric Medicine:

This section will discuss the understanding of quality and patient safety, stepping stones to quality and patient safety, organizational and clinical issues, duty to avoid conflict and the importance of quality for patient safety.

III.A. Patient Safety in the Organization:

Quality and patient safety go hand in hand. These two aspects are expected to be sought after in all healthcare systems. Quality pertains to the care the patient receives. Safety is about the patient and their own personal safety in the healthcare setting. Without proper quality throughout the chain of the system, safety will be hindered because quality ensures patient safety. Certain steps and criteria can be made in order to substantially enact proper quality and safety throughout the entire health system.

III.a.i. <u>Understanding Quality and Patient Safety:</u>

It is truly hard to define quality and patient safety because most of the time these aspects are subjective. Yes, quality can be numeric and patient safety can also be statistical outcomes of certain events, but quality and patient safety are based upon people's own opinions of their care. Hospitals have different opinions of what is satisfactory in their quality of patient safety and their quality in patient care. Healthcare is complex which the system alone is comprised of many differing elements that interact in a variety of ways that need to coexist in a reasonable atmosphere to provide the necessary care to patients.[39] Adding to the complexity of healthcare is the aspect of patient safety. Patient safety can be defined in many ways, however, patient safety is considered the umbrella of care though it truly fits within the realms of quality of care. Patient safety can be defined as the avoidance or prevention of harm stemming from preventable acts rather than errors after the occurrence of the accident.[40]

Safety issues are usually caused because there is a lack in quality of care. If a patient is being unsafe, then the care provided should attend to the fact that the patient is not safe in this particular situation and therefore other safety avenues must be carried out to ensure their patient is not harmed. The medical staff needs to think of the present safety precautions, but also possible foreseeable future instances. Events that occur with a patient being unsafe renders a problem with a lapse in care because there was definite harm to the patient that could have been avoided.[41] These events should not occur often, but if one of these unpredicted events occurs, then action must be taken. Adding the aspect of quality to patient safety allows an understanding of an error and patient satisfaction. Quality of care is defined as the gap between the care actually being delivered and the care that should actually be achieved.[42]

Safety can also be a quantitative figure instead of qualitative. In this case, safety is sought to be about error occurrences. Error is seen as the after effect of poor patient care which

means that error can only become an error if the event has already occurred.[43] All human beings make errors, it is a part of life. However, during patient care, healthcare providers need to think ahead instead of waiting for said instances to occur. If healthcare providers associate patient safety with error then healthcare is at the risk of addressing the issue of the error reduction and the real issue of harm is not prevented nor addressed.[44] Consequently, there will be error even when there are preventable measures taken. Human beings can often challenge the odds. Therefore, as long as there is a chance for error, error should never intentionally lead to harm. Once harm is done, then the problem must be approached through the aspect of quality to force new ideas in order to improve healthcare errors, because harm to the patient is never acceptable.[45]

There are certain criteria in order for established methods to become effective when battling healthcare error due to lack of patient quality of care. Establishing a certain role of standards and sets of rules needs to be specifically defined in the active environment, so some sort of line defining failure or shortcoming of quality assurance can be minimized. While the healthcare provider involved did not intend any safety violations, there should be steps to effectively seek quality of care while battling error.[46] Risks and error should be preventative but are not always humanly possible as noted. The intended event is the patient's safety and quality of care. Error occurs when a risk is taken by the healthcare professional. The purpose of understanding patient safety is to observe, monitor and determine the errors in patient safety in order to correct them. Patient safety needs to be regulated with quality of care to control the risks of the patients in everyday obstacles of care.[47]

III.a.ii. Stepping Stones to Quality and Patient Safety:

The idea of culture and the organization's values are instilled into the work of healthcare providers. The organization should be set up in order to deal with the outcomes of patient risk,

errors, and quality in their care. Safety culture embeds the embodiment of the organizations culture into its employees. It intertwines with the attitudes of the healthcare providers' behaviors so it may flourish.[48] Improving an organization's culture is difficult if ties are already severed between staff and the organization's policies and goals. The culture of the organization is not only difficult to measure but it is also viewed as a low idea on the list of fixing patient safety.[49] Even though culture is listed as last to fix patient safety, culture of the organization can actually enhance the quality and safety of the organization through the attitudes of the healthcare staff. The attitudes of the healthcare providers are vital during patient care because determining the patient's needs are crucial for the quality of their care. Usually the people working for the organization have the same morals and values within the organization itself. With the right safety culture and the right attitudes of the providers, safety and quality of care can advance.[50] In the culture of the organization the lapse in care radiates from the top down. In order for this plan to take action, the organization as a whole needs to be aligned with the core values. The relationship between the physician and patient is crucial for patient safety. The organization's core values need to be copasetic with the physician-patient relationship. The presence of the strong physician-patient relationship is critical to patient safety and the absence of this bond will have the organizations safety protocols fail miserably with physician's lack of culture towards the safety protocols with their patients.[51] The culture of the healthcare system is about attitudes of the people that work for the system and the values that the system holds in order to become a great moral functioning organization.[52]

Understanding the causes of a system's downfall in quality and patient safety relates to the organizational issues. Human errors need to be distinguished between the origins that lie between humans and the behavior which develops within the system.[53] The root of problems in

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patient safety develop from organizational issues. These issues lie from the top down. The key

is to learn from the mistakes and configure solutions to the problems.[54] The communication

between upper and lower management needs to be committed to the human behavior and culture

of the organization. Discussion between management and employees needs to be constructive

and frank in order to address the problems and errors the organization is having in order to

change the occurring problems.[55]

The system cannot thrive unless the organization is committed to the underlying issues.

Healthcare systems are complicated systems designed to run successfully, implementing

technology, infrastructure, and differing opinions in order to create variable avenues to integrate

safety into patient care. Allocating the organization's resources to improve the infrastructure of

the organization will continue the process towards maintaining patient safety.[56] As soon as the

organization discovers what the root cause of their problems are, they are able thrive due to their

ability to address issues and adjust their structure. The organization is thus able to provide their

patients with the highest quality of care and ensure their loved ones that their safety is of the

utmost importance. The system is based upon the authority of safety due to the sole purpose of

the name healthcare. This organization distinguishes itself from other systems to avoid searching

for blame in situations of fault, but to look at improving the organization as a whole through

successfully designed systems; because emphasizing blame does not resolve the problems nor

improve healthcare.[57]

In today's healthcare world, blame should not be placed on certain people, but

approached by actions in order to fix the errors or problems occurring. Systematic thinking

approaches are used in today's healthcare systems in order to replace the blame game during

patient safety initiatives.[58] Most of these initiatives can start with separate committees to which

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physicians and healthcare workers can address challenges they face during patient care regarding their patient's safety. Patient safety committees can adhere to the risks involved in the current patient safety issues and pursue different paths to mandate specific initiatives to generate new patient safety compliance principles.[59] These committees can then put in safety precautions and risk assessments in order to devise a structured plan that can enhance patient safety throughout the system. Safe healthcare organizations build in different assessments, risk management teams, checklists, a debriefing system, and safety reporting teams that open discussion towards better quality of care in patient safety.[60] With these new systems in place, patient safety can improve and become a high standard of care rather than waiting for error to occur.

III.B. Conflicts & Pediatric Consults:

Organizational ethics applies to all parts of a successful healthcare organization.[61] In order for the organization to thrive, pediatric ethic consultations are necessary to access the organizational structure of clinical and organizational issues, avoiding conflicts of interest, and aspects of quality and patient safety. Ethics consultations will conduct, mediate, and comprise a standard to which the next phases in executing decision making and planning will be effective throughout the pediatric healthcare organization.

III.b.i. Organizational and Clinical Issues:

Many organizational issues that arise in pediatric healthcare are due to the fact that most organizational structure is based upon adult medicine and not pediatric medicine.[62] Pediatric medicine is an entirely different field than adult medicine. It is imperative that for reasons pertaining specifically to those differences, the structure of the hospital must be arranged in order to run the organization effectively through proper organizational and ethical means. For instance, in adult medicine adults can understand, contemplate, and decide whether they want certain medical interventions done in their care. Pediatric patients may not have that ability.[63] It

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is hard to see the straight and narrow path in pediatrics when throughout history, pediatric

research and medicine have not been sought after and pediatric medicine is still being developed

today. The medical progress in pediatrics is still being circumnavigated by medical science and

research.[64] Since, there is still not a clear understanding of pediatric oversight in the healthcare

field, physicians, parents, and scientists have a duty to their child patients in order to protect

them from the harms of clinical participation in the medical field. Organizations are trying to

defy goals in pediatrics because the frontier is still a wide open door. There is a fine line

between risk and intervention that induce noble goals that may lead to detrimental consequences

caused by the organization, parents, physicians and scientists even though the ultimate pursuit

was a new defining goal in pediatrics.[65]

Pediatric healthcare organizations are looking to become a new stronghold in the field of

pediatric medicine. Clinical and organizational issues will be futile if there is not a strong

organizational structure with pediatric consultations in place to deal with the issues that may

arise. The setting and organizational structure in pediatric consults also differ from adult

consultations; for example, little attention is paid to the area of pediatric consults.[66] To

transform the need of pediatric ethic consultations, an organization needs to properly set up their

organizational culture from the top down. Organizational culture in pediatrics is a result of the

values and morals of the system portrayed throughout their work ethic. This type of

organizational culture in pediatric ethics consultations may cause subjective speculation. This

may cause disagreements between staff and parents. This is the objective route that most ethics

consultants take because it is objective instead of instilling the values and beliefs of the

organization during a time of confusion for parents and patients. Ethics consultants need to be

neutral territory and not reflect implicit beliefs on the patients and families because it is not their

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place to do so.[67] Organizational culture can be a part of ethics consults, but not so informally to judge and make hasty decisions based on diverging principles. Organizational ethics in pediatric consults are mostly seen during policy and procedure, communication, and cultural organization which identifies the issues in order to approach the problems based on the values and beliefs of the healthcare system.[68] These are not only organizational issues that require ethics consults, but they are areas of the organization that need to evolve in order for the healthcare organization to withstand conflict or eventually it will crumble.

Clinical ethics consults provide a wide range of consults that range from clinical experiences to professional perspectives, combined with personal integrity to discuss the ethical debate at hand within the pediatric realm.[69] The objective atmosphere is crucial when immersing one's self into a clinical case. The consultant is then able to apply ethic knowledge to give quantitative feedback to the children, physician, and their families. During ethics consultations in adult medicine, patients and physicians establish a trusting relationship that is based on the values and goals of the patient. In pediatric medicine the patient may not be able to talk because the patient may be too young to hold a conversation, or not be able to explain the goals to express their true feelings or wants emanating the medical position in which they find themselves. Pediatric ethic consults in clinical situations are based around the struggle of communication, and conflict between healthcare teams, the child patient, and the family.[70] The dismemberment of the healthcare organization through poor organizational means must acknowledge and endorse clinical ethic consults in order to be successful in turn they are trained to know all the specialty services, staff, and information to address issues that arise in patient care regarding the patient's goals and wishes.[71]

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Conflict is usually what drives pediatric consultations. There are three parties that are involved during pediatric care: the patient, the physician and the family. Since this is no longer a strict relationship between the physician and the patient, the triangle of needs and wants is a little harder to circumnavigate. Pediatric ethics consults tend to be driven by conflict and is the most common reason for consultations.[72] Value ethics is an everyday practice in pediatric medicine. The values of the patient, family, and physician need to be understood in order to put the best interests of the patient at the top of the addressed issue list. Consultants need to explore the values of the physician, patient, and family as one of the top priorities because these values are what drive the goals in medicine.[73] Values are what make the patient or family drive to the conclusion that they deny or accept certain aspects of medical care. Values also drive physicians to stand by certain aspects of medicine. This is where ethical conflict can occur because neither party may see the other's side of the argument. The clinical consultant must then see where the true values lie, and where the intended fate of the patient may not be in their best interest.

The problems that tend to arise are usually from a breakdown of communication or the values of the parties involved are conflicted.[74] First, a clinical consult must make themselves see as though they are there to help each party come to a resolution. The consultant must make their space a trustful, calm, and warm place that no one feels threatened by the consult experience. The environment is extremely important during an ethics consult due to the fact that neither party may have called the consult. The consultant must then create an atmosphere of respect in order to bring the physicians and families to an agreement by resolving their conflicts of interest.[75] The conflicts of interest in pediatrics stems from the problem of true informed consent and autonomy. The patient usually cannot speak for themselves or understand the problems that arise in their medical standards to understand the severity of their decision choices.

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All decision making in pediatric care should be a collaborative decision among the physicians, patients, and family members. The physician should include the child in their own care.[76] During the child's initial visits, the physician should reach out to their patient and involve them in their own care because even young children have an understanding of their clinical situations and shared decision making is the best communication.[77] Physicians are now trying to understand their patient as a child. Their values and their interests are just as important as their other adult patients. Physicians are overriding their parent's decisions with their judgment that the child's decision should be respected to the fullest extent. Physicians are starting to understand that even though a child may not understand every ounce of medical terminology, the child can still have a say in their care. Parents may make rash decisions based on their love for their child. However, parents are the closest relationship that a child experiences at their age, and therefore are the proper decision makers. Parents may make decisions, but when children do not want certain care then sometimes it is advisable to encourage the use of mediation between the parents and child. A child's dissent should be final as consultants try to progress to remove overbearing parental decision making and in turn the physician should seek an ethics consult in order to mediate this disagreement.[78] A child's decision should be respected as one of more value than just an afterthought on the way to parental and physician decision making.

Ideally in ethics consults the family and physicians are able to work together to come to a decision in the child's best interests. This of course, is what any consultant would want, but this is not always the case. The goal among these three parties is the child's interests. Integration of the physician and family members' beliefs need to be sought by the consultant in order to actively seek the resolution of the child's best interests.[79] Sometimes, the consultant needs to take a step back and then work towards the goal. Physicians have the problem of their medical

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knowledge is being questioned in these types of situations. Parents think that someone is questioning their morals to which they are deciding care for their child. These two accusations are neither the case. The consultant is ultimately there as a facilitator, to resolve the conflict of interest that arose from the non-consenting autonomous decision of the child. Neither party involved should want to hurt the patient. Each party however, has their own views of the situation. This entails further information, and the understanding of each individual's values during the time of the consultation. The consultant refocuses the ideas of the pediatric patients and the parents during the process of their child's medical situation in order to collaboratively make decisions by being well-informed resulting in optimal care for the child and their best interests.[80]

III.b.iii. Importance of Quality for Patient Safety:

Quality is crucial for patient safety, especially in pediatric care because children are shown to need more protection in healthcare than adults. Clinical ethics consultants are brought into play when organizational issues of patient safety arise. The prevention of organizational conflict is associated with quality improvement in order to effectively develop safety centered patient care that builds on traditional ethics to resolve ethical concerns during a clinical consult.[81] The ethical concerns stem from quality issues in the organization. The ethics consult can decipher the organizational issues that come into play in order to fix the concerns that arrive during the child-patients medical stay. Organization issues of quality and safety need to be addressed during the time of the conflict. The organizational issues lie within the system that does not anticipate the error that could occur rather than catching the error before harm occurs.[82] The ethics consult must enquire, seek information and consult the issues in order to completely attend to the safety of the patient. The consultant addresses the organizational issues of culture, values, and communication during the present consult and must also address these issues for the

future.[83] The ethics consult is crucial for the future of the organization as well. The recurrence of error is not acceptable in the healthcare organization because the aftermath caused by the error is faced by both the patient and quality of the system.

The organizational issues start with the lack of knowledge about policy and procedures in the organization and this lack of knowledge can be detrimental to patient safety.[84] Without knowledge of the organization's safety principles and procedures, the organization can adopt magnitude of risk factors that are not welcome in the healthcare system. Safety is supposed to be understood throughout the system, but if the policy and procedures are not woven and followed throughout the organization, it will fail. Little, if anything helps, after the damage has been done. Communication issues will not help in the situation of promoting safety policies and procedures if they are neglected. Strong quality communication will allow the organization to produce the proper safety skills necessary for children in the hospital. Fixing the communication factor in the organization will help with implementing the safety policies and procedures throughout the entire healthcare organization. Quality of care and implementation of safety for children is more assuring to parents and family members during hospital stays. The ethical framework entrusted to the ethic consult team can creatively implement the new procedures to change the duress of an old failing unknowledgeable organizational framework.[85]

Some problems that may arise during ethics consultations may be due to outside factors, and then modifications to healthcare as a whole needs to be changed and redeveloped. For instance, drug administration in pediatrics is a dominant safety issue.[86] The drug industry is not always regulated by the FDA, which in turn creates organizational policy issues within the pediatric healthcare system, which then differs in the way ethics consultations occur to hopefully mend the safety areas with the patient and family. The limited information of medication dosing,

and safety formalities with children potentially expose them to safety violations which put the child at risk during their medical care. There should be a specialized area of expertise that would encourage evidence based medicine to eventually in the future provide safe and effective treatment.[87] The child patient and family are faced with the problem of their child not having the proper dosing of medication and the unsafe potential of drug medication. This prescription of drugs for children by their physician is problematic towards their safety and the physician's possible medical mal-practice. Physicians are taking a risk by prescribing the unsafe and untested medications for their patients, and healthcare facilities are allowing these policy issues to go unnoticed. Healthcare industries are just as responsible as the physicians in the case that the patients are not being safely cared for by a high quality environment. Drug administration is not the same in pediatric care as in adult care, and the risky medical testing that is not FDA approved needs voluntary reporting from individuals in the system is necessary in order to fix the healthcare system and provide adequate care.[88] Ethics consults can resolve the tension between parents and physicians during the ethical dilemma of administering drugs to child patients. The consultant can also advise the organization to change policy procedures during patient safety when administering drugs for patients.

After a consult has been constructed, all communication and documentation is crucial.[89] The future of the healthcare organization lies in the total force of the ethics consultants to drive in and fix the problem that has risen. Chart documentation during the ethics consult to solve patient safety issues is essential to fixing the problem that currently exists in the organization. In order for other consultants and management to fix or prevent re-occurring problems, chart documentation should be accurate and accounted for during each ethics consult. The documentation of family, physician, and patient views need to be considered and records made

available in order for the safety issues to be ironed out. Quality issues in pediatric hospitals should be set to a higher standard because children need to be guarded by more safety implementation during their care. Lastly, ethics consultants should also educate future physicians, and healthcare management for periodically updating safety guidelines and quality regulations in the healthcare system. By improving communication, and documentation healthcare professionals can educate towards new ideas to spiral into creative quality and safety principles, but it will also create ethical foundations that will surely embark on stronger institutional relationships for the safety of the child patients.[90]

IV. Child Maltreatment Situations: Non-maleficence & Justice:

This section will explain non-maleficence vs. justice, judgments as clinical providers and medical necessities, judgments as the police or protector of the patient, professional duties, organizational responsibilities to protect patients, and using care ethics to manage clinical conflicts of interest.

IV.A. Non-Maleficence vs. Justice & Role Disarray of the Clinical Providers:

Non-maleficence and justice are both vital ethical principles in healthcare, especially dealing with child maltreatment. The first relating to doing no harm which coincides with doing what is good for the patient or beneficence. Justice then entails the principle and scope that no child should have to be treated as a non-human being. The question that engulfs the clinical realm asks, how far does the clinical sphere take these principles and when is it ok to stop? Then again, that goes the same for most cases of when to treat and when to stop treatment. A hospital system has a duty to their patients' to protect them of endangerment or harm. In a pediatric setting, this case is even more prevalent for little humans that are vulnerable, and not able to care for themselves. The organization's culture and proposed didactic training in child abuse scenarios should be identified and updated for the staff's competent knowledge when faced with

an abusive situation. Several studies done on child maltreatment consist of risk indicators for physical abuse and neglect which include: recent life stressors, low maternal education levels, substance abuse, low maternal age, parental death, and sociopathic behavior.[91] Most of the time these situations cause professional conflicts within the role of the clinical physician to bring justice to the patient or to only focus on the current medical situation at hand. This will be further explained in this section.

<u>IV.a.i. Non-Maleficence vs. Justice:</u>

"Primum non nocere which means first or above all do no harm".[92] One of the four principles founded upon bioethics is the concept of do no harm. Non-maleficence is a requirement of the medicine world because people do not go into this field thriving to be masochistic. They enter the field wanting to help and treat, and this is especially true in the pediatric cases. Clinical staff members should intertwine non-maleficence with beneficence in order to produce the most benefit to the patient with the least amount of "harm" because that in itself is essentially their moral obligation and oath to medicine.[93]

Non-maleficence is beyond the act of no harm. It is driven from the values of empathy. Not just compassion, because to be truly non-maleficent a medical provider needs to be able to put themselves in the shoes of the patient. They need to be able to understand and care for their patient as though they have gone through this tragic nightmare with them. It is far greater than compassion alone. It is truly an act of such kindness towards another being to ultimately benefit them, and do everything in medical power to do them no harm. Because without non-maleficence and empathy, medical providers become inhuman and desensitized to situations that need the most sensitivity possible.

The organization's culture in the cases of child maltreatment should adhere to the standards of non-maleficence and justice in order to guide the practice of medical care ethically and appropriately for the best interests of the child patient. Non-maleficence is a vital principal of medical ethics, but it also encompasses beneficence and the respect for autonomy because the patient's interests should always come first.[94] The organization's culture should exude non-maleficence in the sense that all medical staff should do no harm to their patient. As physicians, they inevitably do initial "harm" to the patient or induce pain to provide a net medical benefit to the patient with minimal harm that is encircling beneficence and non-maleficent treatment.[95]

The physician and or medical staff are mandated to report suspected child maltreatment when their patient is being medically treated for abuse of any sort. By not doing this well or at all, poor recognition and reporting of child maltreatment hurts the patient more than preventatively acting in their best interests.[96] The medical staff would intentionally be avoiding reporting or treating the child and that in itself is direct harm to the child rather than non-maleficence and their oath to their patients. Some medical staff members think that their efforts in preventing abuse or neglect are not supportive once the claim is made. However, the idea that medical staff members can make a difference should be instilled in the culture of medicine and these licensed medical professionals should protect their child patients with conviction and bravery.[97]

Many factors can surface as to why clinical staff members do not report on child maltreatment. Some of the common factors consist of: fear of legal reprisal, organizational backlash, loss of the relationship with the family and child, or lack of knowledge to suspect reporting in the first place.[98] The problem with this view is that initially the medical provider is only thinking about themselves and their repercussions rather than the patient at hand. The child

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patient is the one at stake and the one fighting the battle of their life. The medical team should be in their corner and fighting alongside and seeing that their best interests medically and physically are quite possibly not being met in their current situation. Non-maleficence is a binding contract in child maltreatment. When children are being mistreated, their medical team is there to make sure no other harm or pain occurs once they are brought into the medical organization. No further outside abusive harm. No further outside abusive pain. In order to assist medical staff in taking the initiative to report and do the right thing, leadership within the organization should assess the reporting problem and make changes so the medical education needed for pediatricians in maltreatment situations know they are supported when initiating these procedures and know how to tactfully initiate them so they actually do in fact initiate them thus supporting cultural transformation and positive strategies of the organization to uphold the do no harm purgative.[99]

Essentially, all acts to the patient should be in their best interest and that standard should be set at a very high level.[100] This can be communicated between the physician and the child, and if the child cannot speak for themselves then the physician and parents should keep a close relationship to use the best interests' standard and work towards treatment goals together. The truth about children and their physician is not based upon how good of a doctor you are, but how much you care while being a physician.[101]

Justice starts with the initial concept of caring. The balance of caring too much or too little is a scathing process for medical staff because if too much then one may be blinded by crucial information and treat the patient more than they would have before, or to not care at all, or care less could lead to mistakes by not taking enough initiative in the patient's treatment.[102] Caring for a child patient is inevitable, but caring leads to a balance of justice. The justice of the

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patient revolves around how much the physician cares for the patient or whether they can care enough to treat the patient and provide a justifiable diagnosis that is based upon the proper assessment and plan for the child patient. The primary job of the physician should be to make the correct diagnosis of the child patient and provide the proper therapy and other avenues to care for the patient so that unwarranted events will not happen again.[103]

A clinical provider that understands that concept of justice will also be able to create a more ethical climate that promotes justice as well as practices this principle in their daily medical practice and they will be able provide a higher standard in care.[104] The climate of the institution should promote the most ethical practices for their child patients. However, even with the ethical climate, it does rest on the individual medical provider to act in the best interests' of the patient. A primal instinct of medical providers should be that one of their main priorities is helping their patients whose needs have not been met.[105]

Achieving justice is a difficult process and sometimes it is unobtainable and this can be a difficult situation to accept.[106] The problem is that resources and views of justice are mounted at the expense of the clinical provider. Medical providers believe that children have as much equal right as adults.[107] This is in the sense that children are human beings just as much as adults are. This means that each individual whether adult or child is a human and that justice is to each and every human, not just the person who can speak for themselves. Justice not only should and always be a stakeholder in medicine, but it also combines the compassionate and pure emotions of care for the patient and relationship with their medical team. The concept of justice is important to child patient care and above all else provides inherent value to human life.[108]

Bioethics combines the aspect of caring and the component of justifiable actions in order to solve the problem at hand.[109] The principle of justice pertaining to child maltreatment not

only is essential, but must be understood in a compassionate and idyllic way to make an impact in the child's life and the medical providers. The rights of the child patient are essential to all humans, but the first step to reconcile a child's misfortune is to care, listen, and then make a decision that is in their best interest.[110]

The conflict of non-maleficence and justice in a child maltreatment setting is whether the standard of best interests holds true because the best interests taken to hand may be of the parents rather than the patient. However, in a medical situation, a child's best interests should not be superseded by the parent's interest to mistreat the child patient at hand and have their interests beneath that of the parents.[111] When a child presents at the hospital for any type of condition and thoughts of possible child maltreatment are also present, it is the duty of the hospital organization to act in accordance with the child's best interests, hospital standards. It is the moral duty of physicians. The hospital administration and physicians are not required to uphold parental refusals based upon religious convictions, neglect, abuse, or child endangerment.[112]

The principle of justice holds true to this. There is a sense of duty to protect the vulnerable, the weak, and the mute, but it is hard to draw a line when a physician takes their responsibility as a justice leader over being a medical provider. To a child, that white coat can represent their own super hero who is there to save them when they may not be able to save themselves. The physician is their own detective and advocate for their patient. The principle and act of justice should be an act of protection within healthcare and especially in pediatrics. A medical system that defines themselves by ethical practices and values embodies the principles of justice and non-maleficence into the relationships of medical personnel and patient care.[113] In turn, acting in the patient's best interests and supporting their patient in their own accompanying of justice through the proper authorities will rein high and true.

It is hard to be involved in a patient's care without being emotionally invested in the outcome of the patient. It is even harder to desensitize a case that is surrounded by possible maltreatment of a child. Physician's in pediatrics also have a tougher time of realizing their paternalistic approaches to pediatric medicine, and may not decipher their role as the clinical provider or police. A physician acts in the best interest of the patient, but there is a grey area of non-maleficence and justice. The physician does no harm, but still acts to the best of their ability to notify the proper authorities and place the child in the safest environment possible. Physicians need to identify, diagnosis, and treat the suspected treatment at hand and work with all specialty teams as to what is ethically permissible for the safe discharge of the patient.

In most situations of child maltreatment, the physicians see the child patient if: the child has requested to be seen, the child has been brought to the hospital by another staff member, social worker, police officer, or another caregiver because of suspected neglect or abuse, and finally if the child is having a routine physical and the physician sees that the child has symptoms of maltreatment during the medical examination.[114] The medical staff members should be experienced in these situations if they come to light at their healthcare facility. Each staff member should be able to judge the situation and propose proper solutions for the medical necessities of the patient that has been mistreated. "The goals of the medical evaluation" are to infer that there could be other possibilities why the child is having such symptoms when presenting in the medical setting; it is therefore imperative to identify, diagnose, and treat the medical condition at hand by researching the situation for the best possible medical remedy fitting the child patient's best interests.[115]

Diagnosing children that are suspected to be maltreated is a difficult process because during the course of the examination the pediatrician has to be willing to make a diagnosis and

confront the caregivers of the situation alongside a report to Services that will help the child if these acts are presumed real.[116] The physician must be sure that these acts are intentional towards the child and that the caregivers are not acting in the best interests of the patient. It is the duty of the physician to find out as much information as possible from the child patient or guardians whether the child is being maltreated or the past and present medical history of the child is misrepresented.[117] The medical team should document the past and present medical histories so that future encounters with the child are known for their best interests and ultimately the child's own well-being.[118]

Physicians have a duty to their patient to assess their medical needs, and at the same time they are mandated reporters, however, when are they a physician and when are they to act as the police? They are the physician at all times, but they may need to be more authoritative on aspects dealing with child maltreatment. Professionals should address the trauma histories of the child patient to improve their patient's personal well-being and the profession's efficacy.[119] The medical evaluation versus the duty to be a mandated reporter could become conflicted if a physician oversteps their medical knowledge to justice of the peace. The medical evaluation of suspected victim of child abuse should be based upon specific screening criteria conducted by a trained specialized medical provider.[120] Maltreatment can be seen as any physical, sexual or emotional abuse along with neglect of a child.[121] Physicians should report the incidence and discuss these situations with qualified regional child abuse consultants and child protective services so that legal action is not taken against them.[122]

Physicians and other medical staff members should be aware and kept up to date on the laws and regulations on child maltreatment.[123] If medical providers are kept up to date with codes and the proper etiquette then the diagnosis of child maltreatment is easier to catch. This

way, with the knowledge of medical diagnosis and proper training on identifying child maltreatment, the medical providers can focus on the medical piece rather than the justice of the patient by being their protector or police. The physician is the patient's advocate and protector initially by diagnosing their maltreatment situation, but after that they should put the patient's best interests forward and hand the case over to the proper avenues of care and authorities. Medical professionals should be trained in the acknowledgment and the process of child maltreatment so that they can diagnose and then alert the proper authorities or protection services for the child's safety and further medical care.[124]

IV.a.iii. Judgements as the Police or Protector of the Patient:

Child maltreatment such as physical, mental, or sexual abuse is seen as a parental responsibility.[125] The parents or guardians of the child should protect their own child from any harm. If the parent or guardian is incapable of protecting the child, then in their best interest, the healthcare team should take interest in the child's case and give them the proper avenues of care. The complication arises when a physician or medical team take all matters into their own hands and disregard standards of practice with children who have been maltreated. It is a goal of the medical team to reduce the harm and burden of the child by protecting them from maltreatment and report said actions to the proper authorities or protection agencies.[126]

"In 1995, the Children's Bureau of the Department of Health, Education, and Welfare" developed policies that would standardized reporting for medical providers of cases stemming from the maltreatment of children.[127] The factors and documented results of child maltreatment are difficult to prove and even if proven it is the act of the medical providers to assess and report their findings. However, most medical providers may have difficulty reporting and identifying the perpetrator maltreating the child (smith 3). The Children's Bureau made it easier for medical providers to feel more supported in making a child maltreatment claim by immunizing the

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physician from liability, that evidence can be obtained from patient-physician confidentiality in this case, and that medical providers will be charged with a misdemeanor if they fail to report known acts of child maltreatment.[128]

There should be an act of justice. These child patients cannot consent to or sometimes speak to tell us what has happened. Sometimes it is an act of injustice to not seek justice for the patient in need. It is not the sense of finding the perpetrator and being the ultimate protector, but in that moment, the physician is the lead determinant of what direction or path of care is provided. The scope of care does not stop at diagnosis. It encapsulates the full treatment and the full support of all specialties. Just like a diagnosis, it is not a diagnosis of medical organs and failure of systems, it encompasses the body as a whole and the person as a whole. Justice is embraced within the treatment of the patient, but it may be more involved with other specialized individuals, but it starts with the physician.

Child protective services prime responsibility is to protect the child patient, and law enforcement is to investigate the alleged crimes against the child.[129] These two institutions mainly deal with the injustice the child patient has endured. However, it is unclear as to whether a physician should always inquire about abuse, or take matters into their own hands to diagnose certain issues that may have nothing to do with the medical situation at hand. Physicians may see it necessary to ask questions that do not pertain to the medical facts presented to them, but based on a hunch or suspicion may ask irrational questions. The proper examination and medical diagnosis should be the first discovery, and until that is determined, assumptions could lead to affected care. It is important to protect the child, to reduce their suffering, but it is also important to confirm the reasonable suspicion of the abuse to make proper medical decisions for the patient's care.[130]

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Sometimes physicians have too many obstacles in reporting child maltreatment, and are not educated enough, or have a bias against certain types of families that bring their children in for treatment to diagnose the situation and assist effectively.[131] The problem with this is that if a child is being mistreated in any form, it is the duty of the physician to protect their patient and then hand it over to the proper authorities. The physician however, should not assume or have a bias against certain ethnic groups towards those parents who are inappropriately accused of child maltreatment before medical knowledge is gained and proven guilty. The medical team is the examiners, and then the law and proper authorities handle the rest. Physicians and the clinical team should have enough knowledge to examine the patient and be able to work side by side with organizations that protect children in order to hold the offenders accountable for their actions.[132]

The goal is to not overstep professional boundaries, but advocate appropriately for the patient to ensure a safe environment, and ensure preventative measures are taken so that the patient is as safe as possible during and after discharge from the healthcare facility. The physician and medical staff are not the only members of this integrated team; it also includes social workers, other special services, and protective services that require integration of committed individuals to share information and joint decisions to respond appropriately to the situation at hand.[133] The climate should be engaged to effect that support, responsiveness, continuity, and positive attitudes to drive commitment in helping their child patients which is shared between healthcare and protective services to achieve permanent and safe discharges.[134]

IV.B. Obligations to Child Patient by Setting Ethical Standards:

Patient safety is of an upmost importance, but the conflicts of medical care and scope of medical practice may present a blurred vision to clinical physicians dealing with child abuse scenarios. The safety of the child and the role of the physician must stay separate even though

the child patient situation is one of the most difficult to immerse one's self in. The organization's responsibility is to protect the patients, and the physicians' responsibilities are to manage their own moral conflict by defining their moral conflict and attending to the child patient with their clinical expertise.

IV.b.i. Professional Duties:

The physician has choices and decisions to make in a split second. This can be difficult, stressful, and overwhelming for a doctor when having to make these decisions pertaining to a child's life. The moral judgments and values of the physician and duty to their patient hopefully will in fact lead them to the correct moral judgment in making that decision with respect to patient care.[135]

The duty of a physician in pediatrics may use a paternalistic approach. A paternalistic behavior must only be used if it is in the use of the patient's best interests. If there is harm that can come of a child patient, then the physician can use paternalistic behavior to protect the child patient. The physician is obligated and loyal to the child patient, who has trust in the physician to maintain the primary interest of that patient's medical needs

Pediatricians see that the prevention of child maltreatment as a primary goal of medical care, however, they rarely ask specific questions of family violence or other neglectful acts during initial screening of the patient or routine physical examinations.[136] It is hard to ask the child questions pertaining to child abuse or neglect with parents or guardians in the room. Questioning parents or guardians about how they treat their children and whether it is seen as an act to harm the child is an attack on the parent's views of challenging if they are being a great parent or not. Whether the parent does not meet that mark is another story, but questioning their parenting skills in the first place from the parent perspective is not taken lightly as a "shooting the breeze" question during their child's checkup appointment. It is difficult to address the

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parents or guardian of the child about abuse or other neglectful acts when a physician's primary act is the patient's medical needs rather than interrogation of parental screening.[137]

The medical provider's sense of morality based upon the injustices seen in child maltreatment should act in accordance to the actions and intended results of the child's overall well-being.[138] Pediatricians fall in love with the aspect of helping the vulnerable or the child that just needs that extra touch of care with their medical needs. Their sense of moral direction is crucial when a patient is being mistreated and the physician's initial gut feeling of their patient being a victim. The professional duty of the physician is to treat the child's medical needs and assess the patient's social, mental and emotional dimensions so that the child patient can eventually return to a "normal life".[139]

In order to develop this patient-physician relationship to discover these heinous acts that may be condemned upon the innocent child, the physician must create an environment of trust. Medical providers are responsible for the overall environment of care.[140] The medical staff should conduct business that is appropriate for the environment in which the child patient will feel safe and secure. The principle of beneficence defining a medical provider proves to be that the obligation to the child patient is far more than treating the bodily harm, but also to encourage intervention to aim for a higher quality of care for their patient in need.[141]

The physician should know what avenues they can take when a child maltreatment case is presented to them in order to provide protective services, welfare, or prevention opportunities for the child upon diagnosis so that further harm to the child is avoided.[142] Physicians and medical staff are mandated by state law to report any maltreatment of children to the proper authorities.[143] Medical providers are the first line of defense in treating children that have been identified as maltreated. The duty of the physician and medical providers is to medically treat and report

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maltreatment in the best interests of their patient. Physicians and other medical staff members that interact with the child patient should be able to identify indications of maltreatment so that they can recommend proper medical advice or other protective services.[144]

Recognition and prevention are duties of the physician to neither expose the child to further maltreatment nor contribute to failed medical diagnosis.[145] The duty of the physician is not only to recognize maltreatment, but to ultimately prevent it from further reoccurrence. This is not in the sense that the physician becomes the police or the ultimate protector, but by by reporting and ensuring a safe discharge for the child. The physician can act preventatively instead of reactively when the child is later seen again in possibly a worse off situation. The benefit of having an advocate as the patient's medical provider is that the patient will have a better chance of effective treatment and success in life.[146]

The importance of understanding the professional role in child maltreatment is based upon the ethical perception of professional values and sensitivity for the best outcome of their patient.[147] Medical professionals should be aware of their duties and responsibilities to their patient in order to identify alarming situations that may arise. They also should be able to gradually handle the situation delicately with finesse. In the end, a physician's role and duties are to advocate for the patient and their best interests by improving their health and overall well-being.[148]

IV.b.ii. Organizational Responsibilities to Protect Patients:

An organization's ethical climate or culture is what that organization's ethical standards and procedures represent for its system and how to address the ethical problems and issues that arise.[149] An organization's ethical culture is how an organization's moral agency is defined. Understanding ethical culture as the standards the organization holds for its employees and members involved with the organization allows for ethical debate over the company's moral

agent. The values, procedures, and policies within the organization should coincide with the organization's culture to protect, and provide for their child patients and their best interests. The organizational responsibilities should be known and acknowledged throughout the healthcare system and embedded within staff members' responsibilities within each and every job description.

When a healthcare organization interacts with child abuse situations of any notion, it should recognize, report, and try to prevent the situation from ever happening again. The safety of the child in these cases, should not be taken lightly. The organization and community's efforts should be focused on the child patient safety efforts that are in place to serve as individualized care that can identify and react to certain risk factors.[150]

"Laws, policies, and procedures" are enacted to protect a child to ensure their rights as a human being and to encourage safety guards to promote the child's well-being.[151] Protection of child's rights is imperative in the healthcare field especially since medical staff are mandated reporters and the healthcare organization is liable for the injury or harm of the patient in the act that the facility does not preclude an unsafe discharge. Most organizations dealing with children adopt a paternalistic approach upon dealing with a vulnerable population that should be protected by laws, policies, and procedures. Most states have implemented many laws for the protection of children, and the primary responsibility of the child falls on individual state laws and systems to provide appropriate care for the maltreated child.[152]

Children, in general at the beginning stages in their life, are not able to speak for themselves, and therefore need adults such as their physician to function as their advocates.[153] The physician and medical team should be experienced through differing trainings, education, and on hand experience. With these proper training sessions, organizations can provide

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experienced personnel that promotes advocating care for the child patient among the state's legal procedures, and the organization's policies that will contribute to obtaining crucial information from the patient or others involved in the maltreatment cases.[154]

The organization's culture and environment should promote the emergence of beneficence and justice for the child maltreated patient. Alongside the principle of non-maleficence to do no further harm and promote their best interests. When a child patient or guardian seeks help in the emergency department because maltreatment the response of the organization and medical team should be a benefit harm analysis and early detection of maltreatment response.[155] The trained medical staff can then empathetically attempt to serve the ethical dilemma of helping the child patient or allowing personal feelings evolve that may in turn harm the patient more than benefiting them.[156]

The organization's methods and procedures when a child patient comes in with maltreatment concerns should be accommodating. They should also hold their standard of care at the highest level when dealing with these extremely sensitive situations. All information should be well documented and given to the proper authorities and other organizations such as police, forensic teams, or other legal authorities so if present simultaneously, it reduces harmful or hurtful questions that the patient or guardian may have to answer.[157]

Documentation is so important to communicate and provide for a child maltreatment case. By having these forensics and screening strategies implemented in an organization to assist in identifying and documenting these cases, abuse, neglect, or maltreatment analysis ultimately makes for quicker allowances for treatment for the child patient as well as a safer discharge if information is more readily available for the proper authorities to react.[158] "Key statements or quotes should be copied verbatim" so that this crucial information is documented appropriately,

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accurately and reliably so the depth of the situation is fully understood when the proper authorities take over the case.[159] There is a certain understanding that the medical team and pediatric organizations should think two steps ahead in order to provide a higher quality and protected care for their child patients. It is the moral duty of the organization and medical staff members to be non-maleficent and act in the patient's best interests in order to go beyond "normal" practice and rise above to achieve a practice that centers around the moral, ethical, and empathetic obligation to our patients.[160]

Child advocacy should already be a primary value in a healthcare organization and the people that work for a children's institution. Prevention of further abuse should be evidently convincing based upon the skills to recognize and report the act of child abuse. This said, the avenues of prevention should start with the physician, and healthcare organization, alongside the community and government to ultimately lower the chances of long term child abuse prevention.[161] Children in such a vulnerable state may not confide in these tragic memories of abuse nor may they make sense when telling their story of abuse. They just may not have the vocabulary to explain what occurred. Proper education for employees and the organization as a whole will add to child advocacy and patient safety. The organization along with society cannot improve the justice system alone, the preparation and continuing education of child abuse should be maximized by all efforts and the child patient should have credibility and advocacy on their side.[162]

IV.b.iii. Using Care Ethics to Manage Clinical Conflicts of Interest:

The patient-physician relationship or with children the triangle that includes the parents or guardians of the child is crucial when dealing with difficult cases. The communication, the respect, and the care are all hinge upon the relationship and bond between families and medicine.

The medical field defines the patient-physician relationship as a duty to uphold the patient's needs or welfare until a fee is paid, however, these boundaries are blurred when trust and compassion are no longer limitations, but stakeholders in care.[163]

Care ethics can ground the conflict of interest that resides in the physician or medical staff members' conundrum of whether to fight for their patient's justice or to act only as their medical provider. The physician and medical team can use their own personal autonomy as a set principle to fight or just express medical facts as an expression of their clinical judgment that is based upon expert knowledge in their field to best define solutions to the problem brought before them.[164] Care ethics is especially important in pediatrics. Care ethics embodies the culture of the organization and the mission to help patients. In pediatrics, physicians and medical staff members along with the family create a bond to ensure that the patient is achieving the best care possible. This type of ethics involves a team atmosphere and the relationship between medical providers, family, and patient all stem from the values and compassion embraced for the goal of quality care.

The idea of care in the patient's best interests is backed by the ethics principles: autonomy, beneficence, non-maleficence, and justice. The medical team can act in either direction according to the principles by using their personal autonomy to decide the patient's best interests and do no harm while still providing quality medical care and appointing appropriate avenues for justice of their patient. Even though the medical team acts in the best interests of the patient, and non-maleficently, the medical providers need to be aware of being too paternalistic in cases where a child can speak for themselves. Paternalism can violate patient autonomy or process in care because the focus is driven about medical outcomes and not necessarily everything that the patient would want to have done or go through.[165]

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Teamwork will enhance continuity of care and ultimately make a commitment as it is as a whole team to take responsibility for their patient's care that requires professional values and moral competence.[166] Care ethics in the sense that values, morals, and ethics are a priority in care will essentially solve conflicts of interest by taking the time to care for the patient in need. This aspect of care goes farther than just compassion. True care is empathy for their patient, to be able to put themselves in the situation and feel their own patient's pain. Compassion is a value that someone either has or doesn't, but empathy is something learned or taught. Empathy is a value that medical members should be taught and retaught so that it is not lost or forgotten. Desensitization in the field of pediatrics and especially in the cases of child maltreatment causes more conflict and more harm to the patient rather than the goal of protection and safety. Beyond the scope of medical practice, medical staff members need to be competent in the values and processes of the organization to obtain the accurate diagnosis of child maltreatment and aim to better themselves as medical providers with strong advocacy for their patient's rights.[167]

The external goods that society imparts on healthcare such as: culture, environment, norms, trends, and quality can affect the healthcare systems internal goods such as the clinical members of the institution and the organization's policies and procedures.[168] Directly assessing child maltreatment and managing the clinical conflict between evaluating clinical treatments versus justice for the patient is a difficult environment. The healthcare systems act to apply changing norms and standards of care that society views appropriate could also in turn affect the internal organizations climate to change with the new views of care. The child patient as a whole is part of medical care. In turn, the values of compassion, empathy, trust, and respect are inseparable to acting in the patient's best interests. The medical staff needs to understand and

become competent in the education of child maltreatment in order to recognize, treat, and protect so that as medical providers they lower the threshold for future cases of child maltreatment.[169]

V. Conclusion:

Organizational ethics thrives through the healthcare organization when making decisions during conflicts, patient safety, and clinical issues. These aspects of care are not only driven by moral agency, but are driven by the means of clinical issues not being resolved, conflicts of interest erupting between families and physicians, and the quality of care that leads to a deficiency in patient safety. Organizational ethics and moral agency of the organization is poorly defined through its system if the ethics consultant needs to repetitively consult on these matters of care. This clearly indicates the urgency to have a change in the organizational structure in order for care to be properly received. Management and ethics consultants will then be able to discuss different avenues to congruently change the way the organization is run in order to produce the best care in pediatric healthcare. The patient is the only priority, and in order to properly care for them these issues need to be addressed. Ethics consults are needed for healthcare organizations to understand their organizational issues and be able to address them accordingly to pursue persistent quality pediatric care.

The involvement of healthcare ethics in child maltreatment situations is becoming more pertinent. The framework of ethics exists already within most healthcare organization's because most mission statements and goals of facilities is to care for their child patient, make a safe environment, and treat them pertaining to their best interests. This especially holds true with pediatric organizations. Encouraging an active medical staff and proper educational proceedings throughout their professional training of child maltreatment, clinical staff will be better prepared for conflicting ethical situations in the future. Training and the proper clinical environment are

the backbones to providing a safer and less stressful dilemma and provides a higher quality of care. The stress of the medical teams are best reduced by implementing the best interests' standard of the patient to lead the drive for safe and supported care.

Empathy and compassion of course are needed to initialize the response of diagnosis and treatment alongside the moral duty to protect. All of these values, missions, morals, and ethics are embedded within medicine, but it is the right type of organization, medical team members, and culture that has the most beneficial effect on these tiny patients. It is that assembly of parts that truly benefit the patient, staff, and ultimately drive quality healthcare. Healthcare ethics is the fulcrum for quality effective care. Ethics is always present, and it is the glue that will drive recognition, diagnosis, relieve stress, and prevent child maltreatment for the benefit of the patient and justice for future children.

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Chapter 5: Ethics Consultation Quality in the Clinical Setting of Pediatric Medicine:

Pediatric medicine is not only a specialty that holds the best interests of a child patient at the sole root of medical treatment agendas, but also a specialty that has medical personnel caring so deeply about those that can't always speak for themselves. This medicine not only is a compassionate practice, but it serves as a service to promote the best of interests for children who have never had a chance to promote their own well-being. This world of healthcare is far from the adult world and needs a helping hand to develop a higher quality of care for these pediatric patients. Compassion is essential when caring for children, but it also may be too paternalistic for a proper ethical environment. Pediatric medicine is in a developing stage of pediatric ethics consultations whereas adult medicine has developed standardized ethics consultation practices. In the case of pediatric ethics consultations, the medical practice will need to develop quality ethical care specifically rendered towards pediatric patients. The nature of clinical ethics lends its hand more towards adult medicine, which needs to now partake in pediatric care. The version of clinical ethics that should be more prone to pediatrics is care ethics. This ethic should be used based upon the child vulnerability, compassion, and enforcing quality care.

Genetics is an intricate science which enables humans to discover knowledge of human characteristics made from genes. These characteristics include hair color or eye color, but also include disease or syndromes that affect a person's quality of life. New technology can potentially annihilate unwarranted diseases and progress towards preventative care and personalized medicine. The imbalance of knowledge between science and medical concepts with regards to genetic testing possesses the need for ethics consultation services to solve the pragmatic ethical issues upon genetic screening in medicine. Genetic screening and stem cell

treatment are growing desires in the medical field. Each of these tests are done to support healthier children. Ethics consultation services should be used in order to inform people of their genetic decisions whether it be genetic screening, enhancement, early prevention, treatment, or preventing a slippery slope of societal consequences. Education will be key for an ethics consultation service to bridge the conceptual gap of understanding versus misconstrued information in the new age of genetic screening.

II. Ethics of Care & Surrogate Decision Making:

This section will discuss the nature of clinical ethics, care ethics in pediatrics, committee, individual and team approach, problems with informed consent, surrogacy and best interests standards, and quality clinical ethics consultation.

II.A. Ethics of Care in Pediatric Medicine:

This section will discuss the nature of clinical ethics and tailor it towards pediatric medicine. The 'ethics of care' is the preferred model of pediatric ethics because it defines a comfort of ethical duty to the child patient and surrogates who speak or act in the best interests of the child patient during a difficult time in the child patient's life. Children may or may not be able to understand their medical needs, treatment plans, diagnosis, or wishes during their care, but it is the duty of the medical team and ethics consultant to provide a better understanding to either the coherent patient or the surrogate.

II.a.i. The Nature of Clinical Ethics:

The term clinical is defined as the physician-patient relationship and ethics is the moral judgment of what is right or wrong.[1] Clinical can now be described as more than a physician-patient relationship to include all specialties pertaining to individualized needs. Ethics will dutifully fit into the new clinical meaning, by being a specialty group requiring a specific setting

of care. Combining these two concepts together allows for another judgment of moral duty during the patient's care. The term clinical ethics is not new, but the need for resolving these ethical dilemmas is more prominent now more than ever.[2]

The ethical issues that are regularly present in medical care of a patient can conflict with the physician's understanding and resolution to their patient's current medical problem.[3] Sometimes, the physicians that have taken the Hippocratic Oath see that some duties as a physician do not fit the duties as an ethicist. Physicians see a duty to heal and to not harm the patient which can conflict with quality of life issues or end of life care. In these situations, clinical ethics can guide the practice of medicine through the embodiment of the core principles of ethics in order to find a common ground in a conflicting situation.[4]

Clinical ethics can resolve much conflict in many situations that involves diverging views in a patient's care. Conflicts have been dissolved by clinical ethicists because they involve patient autonomy and moral preferences as the moral truth to resolving conflict.[5] Medicine provides patient care and ethics aides in delivering patient care that is attributing to their personal values. The development of clinical ethics and ethics consultants emerged through the ethical reflection of patient care to ultimately let ethical guidelines safely guide patient care.[6]

Throughout clinical history, there have been misuses of science, medicine, technology and human right. These shortcomings are undeniably an atrocity that has been rendered clinically inappropriate and now is rightly being avowed by clinical ethics consultations and clinical ethics frameworks. There is no mere truth or mere falsehood in clinical ethics, but it rather is a willed negotiation of societal choices, moral truths, natural selection, and value judgments which make up human rights which should never be violated.[7]

The advantage of having clinical ethics in the healthcare field allows for multiple specialized disciplines to meet the need of the individualized problem.[8] The structure of clinical ethics has not been a concrete model because clinical ethics is individualized to certain patients' and medical staffs' needs, wishes, values, and goals. Therefore, implementing a team atmosphere allows for specialties of all natures to be a part of the care plan that best fits each patient to ensure the best ethics strategy to elicit professional conduct guided by ethical frameworks.[9]

II.a.ii Committee, Individual, Team Approach:

Regardless of the consultation service, whether team, committee, or individual, the American Society of Bioethics and Humanities, ASBH, core competencies for healthcare ethics consultations must be represented throughout the consultation.[10] The consultant is the key mediator that embraces the core competencies in order to facilitate proper quality of care to the patient and the medical staff in conflicting situations. It is best that the consultant analyze the problem, process the situation, and run an effective ethics consultation service.[11]

The team process or group process incorporates the expertise of all specialties relevant and necessary to the clinical case whom have knowledge of the relevant information.[12] This route of clinical ethics consultation provides specialized knowledge at the immediate intervention of the ethics consultation. This involved care informs the whole team of detailed information rather than charting, writing, or verbally providing disconnected information throughout the team. It is important for everyone involved in the healthcare team including the patient and family to use their resources to carefully consider the ethical concerns to form feasible options for the future.[13]

The purpose of the ethics committee is to improve transitional public relations, education, development of policy and guidelines, or consultation services to suggest bureaucratic decisions to resolve complex clinical ethical dilemmas.[14] The committee is built with individual specialties that could include: legal, social work, case management, physicians, nursing, civilians, and non-clinical administrators. This work ethic of a committee provides deliberation of ethical issues in a forum to include all conceptual ideas that could permit possible ethical conclusions based upon a specialized body of knowledge. By having an ethics committee, the hospital can integrate the community and clinical practice among the representing experts to advocate a strong role for clinical ethics consultations.[15]

The individual ethics consultant has the task of merging together ethical issues that range from social, legal, theological, economic, and political which need to be separated and developed into what is morally relevant to the clinical ethics case.[16] This individual ethics consultation model allows for the ethics consultant to be more one on one with the patient which encourages a stronger trusting relationship between the clinical side and the patient advocate side. The consultant has the opportunity to know the patient as a person and not just as a medical anomaly and can therefore interpret better the patient's pertinent values and attitudes.[17]

All interpretations of clinical ethics consultation services previously discussed are able to be implemented in any form throughout a healthcare system. However, accepting a range of consultation services in a hospital may be even more appropriate because every case is exceptionally different on its own. Ethics consultation services focus on providing a service that addresses any ethics issues that arise in a particular case by team based approach, individual or community group depending on the ethical dilemma at the time of the consultation.[18]

An ethics consultation format for most scenarios have a typical procedure on how to move about the consultation. Once the request is verified, a consultant should gather information from all parties involved in the situation to best understand the patient's values and wishes, and the medical staff's opinion of the best scenarios for care.[19] The job of the consultant is to best analyze the situation to come to the conclusion through multiple conversations with patient and medical staff to resolve the ethical problems. More often than not, if all parties are included in the individuals' care, and are able to express their views about the situation, it is easier to come to an ethical conclusion in care based upon all specialties involved in the individualized situation.[20] After assembling the proper team and evaluating the situation, this centralized care unit can work through the case to facilitate the proper ethical conclusion.[21]

Shared decision making includes the primary physician team, family, patient if competent, and any other specialties involved in the patient's care. Miscommunication may be the reason to why the patient and or family are resisting in certain measures of care. A family meeting allows for decisions to be made with no misconceptions, misunderstandings, or mistreatment. Each person is able to play a critical role in the treatment process of the patient. Shared decision making is a back and forth process that may take more than one meeting with the patient and or family to correct misunderstandings making it easier to understand and to accept recommendations so as to share in the continuum of care.[22]

After a team meeting has been completed, the discussion and plan should be documented in the patient's chart ensuring that the recommendations are clear so that misunderstandings are avoided in future care.[23] Documentation is crucial so that it states the patients' wishes, and goals of care so that if at any time a patient becomes incapacitated, the medical team and ethics can be their advocate. Once all information is gathered, and a conclusion has been made, the consultant

should follow up with the case and learn what was done, assess how the service was perceived, and ask for feedback.[24]

The aims of an ethics consultation is to envelop some of the core competencies such as: listening well, recognizing the barriers of communication gaps, representing views of all parties involved, demonstrating sensitivity to the medical team and patient, and negotiating a distinguished well documented approach to clinical ethics in medicine.[25] Implementing these areas of expertise in a clinical ethics consultation bridges the communication gap between patient and physician. The implementation of any type of ethics consultations will address the uncertainty or conflicts that typically emerge pertaining to patient care.[26]

II.a.iii. Care Ethics in Pediatrics:

If any profession is normatively good, any relationship will require professional good or virtue.[27] The profession of ethics in pediatric medicine requires good moral virtue stemming from individuals' characters and the children's system itself to develop a 'care ethic'. This ethic should perpetuate through the system by the time a patient comes through the doors of the medical facility. This ethic should be embedded into the care of each individual child and should embody the virtues of compassion, empathy, trust, respect, and faith. The focus of care should be a moral quality in itself so that the ethics of care can guide us to what is morally acceptable and what is morally wrong.[28]

Ideally if medical professionals could be taught to be ethically and morally just then patient care could always be attained at a just level. However, we do not live in a perfect world and we do not always spend the time or exchange information that can change the care in medicine. We do nevertheless have ethical framework, education, and proactive clinical ethicists to help guide the appropriate medical care for pediatric patients. In the perfect medical world, physicians and nurses would theoretically have a list of each skill, values, virtues that would

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achieve the desired physician or nurse, and this world optimally attain the goals of ethical medicine.[29]

In the present medical arena, ethics may also be considered 'virtue ethics' which will guide pediatrics to attain the goals of ethical medicine. This type of ethics requires qualities that are necessary to achieve excellent internal medicine and attaining the best for humans as a top priority above all other circumstances.[30] The human being and in this case the child is the most important priority to the medical care team. The virtuous acts that an individual possess comes from within a person's true character that drives their views, opinions, and actions. Virtue is one of the oldest and most durable concepts of ethical theory. These virtues cannot be easily separated from the reason, emotion, and practical judgment a person must use to take action to resolve a problem.[31]

In order to value care ethics, the concept of empathy should be set in the forefront of care when accommodating the needs of the key role-players in difficult conflicting ethical situations.[32] This is an absolute in ethics. The concept of empathy should be intertwined when difficult situations arise because no one knows what the other person is going through. People are inherently different. This should be respected by being empathetic towards parents or surrogates that are living through their child's life altering medical situation. No one's pain is the same and in that instance all a person can do is be empathetic to their individualized situation. Understanding and wise judgment helps identify the emotions complexity of the particular situation and acknowledges the motivation of the personal concerns, vulnerabilities, and problems arising because of a person's deepest fears by being flexible in assessing the situation.[33]

There is a therapeutic goal to care ethics to heal the conflicting situation that poses what moral judgments should be made for the patient's optimal treatment plan. Care ethics entails the ethics consultant to bridge moral norms, virtue ethics, ethical frameworks, and constituted medical judgment to engage the therapeutic goal. The concept of justice and virtue ethics cannot stand on their own and require ethical theory and moral philosophy to withstand the scrutiny of medical science to ensure what is rightfully owed to the patient.[34]

The virtue ethicist is able to register their feelings of their human experiences and be able to approach ethical dilemmas by stripping away emotional responses to reason with a plausible solution that is developed through being a pivotal moral agent for the patient at hand.[35] This moral agent who processes ethics consults is ideally a key figure to promote the wishes and best interests throughout their medical care for pediatric patients. This ethicist for pediatrics should not only use the care ethic model, but should also intertwine an ethical framework. Ethicists should approach the particular situation with moral reasoning, sensitivity, and right action to manifest care.[36]

II.B. Surrogacy & Best Interests in Pediatric Medicine:

Problems that ensue clinical ethics consultations in pediatrics deal with informed consent and surrogate decision makers. Surrogate decision makers can come in many forms, however, the surrogate should use the best interest's standard to make informed decisions. These decisions should be made with the patient's wishes at hand by the surrogate that is continuously informed with adequate information to make proper decisions for the patient that cannot relay their wishes. Informed consent should be properly administered even if the patient cannot decide themselves. Clinicians rely on the patient designated surrogate or next of kin surrogate to make informed treatment decisions for patients that cannot or no longer can decide themselves. [37]

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Physicians should offer information that the patient or parents can understand, comprehend, and interpret in their own language. The physician should also offer alternative methods or other optional avenues if the patient is seeking other paths of care. Patients and or surrogates should not be persuaded, or coerced into a treatment plan that they are not comfortable with because they feel manipulated into the situation by inaccurate data.[38]

Sometimes patients who are lacking capacity may not actually be lacking capacity, but they do not understand the information given to them and more time and energy should be spent to facilitate understanding.[39] In pediatrics, children may be able to understand their medical anomaly if it is interpreted in a form that they can understand. Failure to give adequate information for a procedure, medication, treatment, blood draw, exams, or diagnostic tests will promote a false positive of a patient lacking capacity. Legally, competent patients must be informed of risks of the proposed treatment plan or other diagnostics in order to have the right to refuse or accept options of care.[40]

Competent patients are allowed to refuse virtually any treatment even if this treatment shortens their lives and leads to death.[41] Patients that are seen as having capacity are able to make their own healthcare decisions based upon the medical information provided, a risk benefit analysis to their own personal quality of life assessment, and deduction of consequences of their actions. This could reside in older teenagers who can clearly analyze the information given to them and assess their medical situation based upon their wishes and goals of their own medical care. Each patient may vary on their conclusion to medical decisions, but no matter their decision, it should be respected even if their decision seems ill advised. The ethical concept of autonomy allows for the refusal of care by a competent and informed patient which is supported by American law even if the decision results in an earlier life span.[42]

Exceptions to informed consent are in emergency situations and in this case it is called implied consent. In emergency situations, patients may not be able to express their wishes or give preference to consent to treatment; however, physicians presume that any patient would give consent to treatment because the alternative would be disability or death.[43] In this situation, it is called implied consent to which most people would want to live rather than induce pain or suffering or possibly death. Sometimes with Jehovah's Witness they do not take blood products, but with pediatric patients' brought to the hospital, the patient will be given life sustaining blood products whether the family denies the consent or not. The principles beneficence and non-maleficence provide the physician to benefit their patient and to do no harm which in emergency situations a physician will save lives provided by ethics and the Hippocratic Oath.[44]

Approximately 95 million Americans cannot read an informed consent document because they are written typically at higher reading level than an average Americans which is an eighth grade reading level. This does not meet the standard consent that federal standards has set for readability and process ability.[45] If parents or child patients' cannot read a standard informed consent document nor have a medical personnel explain the document in a way that they can understand then the process of informed consent is truly not informed. Pediatric informed consent forms have been found to be written at a graduate school reading level which warrants serious concern. Efforts should be made to review the material with parents and children until there comprehension.

It is a difficult task to judge whether a patient has capacity to give consent especially in pediatrics. Most pediatricians with older teen age patients look to the parents to give informed consent to procedures or diagnostic testing. Ethics consultation services can provide a standard of improved informed consent or education on how to improve the process of consent in

pediatrics. There are no clear standards to judging capacity of a patient in order for them to give consent, but models of expert judgment are being developed.[46]

Giving parents more time and given the opportunity to consult other family members, the need for repetition of information, what the next steps are in patient care, and when the next discussion or decision needs to be made allows for informed consent to be detailed and tailored to individual parental needs.[47] Clinical ethics consultations can help facilitate the basic need of informed consent with individualizing care for the patient and family. The consultant is able to bridge the information gap and attain quality care with the medical team, patient, and family all in congruent understanding of the medical process. Ethical analysis, standards of care, policy formation, basic analysis, and informed consent are essential for families struggling with these difficult choices, but providing these basic needs allows for a quality consensus in care.[48]

II.b.ii. Surrogacy and Best Interest Standards:

Once a patient lacks capacity, a surrogate is selected to make decisions for the patient who usually is selected previously by the patient themselves, but in some cases is court-appointed.[49] In a case with a pediatric patient, the patient is always considered to lack capacity because primarily until a mature age, a child cannot make their own independent healthcare decisions. If the patient never had capacity, then the medical decision should be made in the patient's best interests by describing the patient's loves, beliefs, or fundamental moral commitments if possible.[50]

In 1925, the Supreme Court officially decided that parents can make decisions on behalf of the child minor based upon parental autonomy and should be recognized as a parental right.[51] The court-appointed surrogate is assigned in cases that a patient does not have any family or friends or in a case where family and friends are not willing to make medical decisions for the patient. Most times, the court-appointed surrogate will side with standards of care physicians'

suggestions. This type of surrogate decision maker cannot take away life sustaining treatment unless the patient is imminently dying. However, to make those end of life decisions, the patterns of the person's life, or other information about their values, goals, preferences, and wishes are helpful to come to a useful end of life care decision about the patient at hand.[52]

The next of kin or NOK, if assigned, will assume the surrogate responsibilities and become the decision maker in terms of familial law.[53] In Pennsylvania, the NOK order goes as such: spouse and any children from previous marriage, kids, parents, sisters or brothers etc. This surrogate also uses substituted judgment which relies on the known preferences of the patient to reach a conclusion about medical treatment which usually stems from the familiarity with the patient's values and beliefs or the patient has previously stated their expressed wishes.[54] Again, in pediatrics it would also go in the same order as parents being the first next of kin surrogate. To override parental authority there would need to be clear and convincing evidence that the child patient has been harmed, neglected, or a serious threat to danger has been posed which could relinquish custody of the child temporarily or permanently.[55] The physicians and NOK can work together to determine the best interests of the patient and goals in line with different medical avenues available. Physicians can also offer suggestions or recommendations if they have known preferences of the patient.[56]

The ideal embodiment of informed consent lies with the surrogate-physician relationship and the surrogate should interject the patient's values in the decision making process to the best of their knowledge to make an informed decision based upon medical facts provided.[57] These surrogates are either chosen to help the patient through their documentation of directives or they know enough about the patient to drive their medical care based upon the patient's values. If the patient cannot speak, which in most pediatric cases they cannot, then the parent should act in the

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best interest of the child. The goal of medical care through the informed consent process either directs information to the surrogate or to the patient in order to carry out medical care based upon the patient's goals and values instead of interpretation by their physician.[58]

Most of the time the child patient's best interests are determined by one on one conversation with the patient if applicable or with the parents of the infant child. The best interest's standard requires the surrogate's decision to promote the patient's best interests by: promoting the patient's welfare, making choices namely about relief of suffering, preservation or restoration of function, and the extent and sustained quality of life that reasonable persons in similar circumstances would be obliged too.[59] However, this standard is scrutinized because the individualistic knowledge from the child is unknown, vague and can be open to dangerous abuse.[60] The best interests of the child should take into account all specialty physicians, nursing staff, care teams involved, and make the best interest standard as a team effort. This standard should give direction to the current medical situation and promote the maximum good to the individual patient at hand by focusing on the multiple alternative options, minimizing net harms, and promoting the child's rights by judging what is best.[61]

Physicians may see some decisions as unwise or foolish, but those decisions may be in line with the patient's personal values and in turn they are allowed to make their own medical decisions.[62] Patients need someone to fight for their wishes when they cannot or have never been able too by having someone stand as their voice and make decisions based upon their best interests. In the end, surrogates and physicians need to think what is best for the patient and make sure it considers their best interests instead of what the surrogates or doctors would choose for themselves.[63]

Subjective thinking and decision making are usually made on the basis of the principle of beneficence, autonomy, and the discussion about quality of life. Most people have varying degrees of what aspects of life are acceptable to them. This diversity can create many ethical problems pertaining to: lack of understanding of patient's own values, bias and discrimination that negatively affect the physician's dedication to the patient's welfare, and lastly, the introduction of social worth criteria into quality of life judgments.[64]

Patients know their own values and preferences and determine which risks and side effects are acceptable.[65] Depending on the age of the patient, lack of understanding of the patient's values may drive medical care in differing non-value laden avenues which the patient will not be comfortable with. Essentially, even if the patient lacks capacity to decide what they would want in particular situations, or in the case of infants, it is the physicians' or medical staffs' responsibility with the parents, if applicable, to depict what they would want. Quality of life issues extend to rehabilitation, palliative care, treatment of chronic pain, and enhancement that can always be ethical conundrums when information is not passed appropriately.[66]

Bias and discrimination that negatively affect the physicians' outlook of the patient and or care given can be caused by delusions or false beliefs or incorrect inferences, and negatively affect patient care.[67] Physicians' and or medical staff should independently make their objective medical assumptions about the patient after they have physically seen them. The principle of justice, distributes fairness equitably among everyone, and demands equal transactions among every participant which reasonably, they deserve without unfair exploitation, deceit, manipulation or discrimination.[68]

Lastly, quality of life refers to the degree of satisfaction that people experience life as a whole pertaining to physical and mental health and well-being.[69] Everyone's beliefs are different

and should be respected in the sense that the child patient's best interests are at the heart of the medical conundrum. The best interests standard demands parents focus on the child's current needs and response to social mores, values, and situational stability.[70] Promoting the patient's legitimate interests uses the principle of beneficence, meaning doing well by the patient, and raising the doctor patient relationship to a more interconnected level.[71]

II.b.iii. A Quality Ethics Consultation:

Anencephaly occurs in approximately every one in one thousand pregnancies worldwide. It effects the neural tube due to an abnormal tube closure in the brain which usually occurs in the fourth week old embryo causing major portions of the scalp, skull, and brain not to form. Many of these babies are born still birth, and if alive, there are no interventions supported for life.[72] This disease is non-curative and an emotionally torture some disease for the parents and baby. Due to the fact that anencephalic infants primarily do not live for very long, organ harvesting from anencephalic infants has always been questioned. This case brings into question: the best interests standard, organ procurement, aggressive medical care, religious views, consent, the legal system, ethics, and futility. This case is one of the turning points in medical futility, and is based on determining whether aggressive life sustaining treatment supersedes the best interests of the patient to preserve life against medical advice and should this be honored or condemned.[73]

Baby K was born cesarean, in October 1992, she was an anencephalic infant that had trouble breathing and was put on ventilator support for almost two years until she passed away by cardiac arrest.[74] The mother of Baby K had previous knowledge of the anencephalic disease and was notified of the possible issues at birth which prompted the pediatricians to suggest termination of the pregnancy, however, the mother's wishes and values were that all human life has value and God will work a miracle if that is his will.[75]

Upon birth, the mother insisted on aggressive measures including cardiopulmonary resuscitation along with ventilator support to keep the baby alive as long as possible even though all of the neonatologists, intensivists, and pediatricians considered this outside the standard of care practice for anencephalic newborns.[76] To the best of all specialty knowledge, Baby K could not think or feel.[77]

There are many legal considerations to this case that pertain to constitutional law stating that clear and convincing evidence to go against the decision maker must be made in order to go against the mother. The rehabilitation act of 1973 should not discriminate handicapped individuals based solely on their genetic defect, and EMTALA states that any emergency situation should be stabilized and does not exempt futility clauses.[78] All in all, because the infant cannot make decisions for themselves, the parents are the rightful decision makers, but do not however, have the right to mistreat their children and choose medically unreasonable treatment alternatives.[79]

An ethics consultation should have been placed during this ethical quandary of whether to limit life sustaining treatment options or to continue with aggressive treatment. This case could have been handled more accordingly with the standards of medical ethics, medicine, and law if an ethicist would have been on hand. The ethicist would have been able to interpret the goal of the mother and medical teams wishes and been able to configure the best solution under the rather intense circumstances that ethically fit the best interests of the child, quality of life, palliation of symptoms rather than qualifying what is deemed right or wrong, but morally justifiable based upon the disease.[80]

The question to ask is can we allow this baby to die morally justifiably and within the ethical realm of medical practice? An ethics consultation will be able to provide different

ethically justified routes to this case and propose the conflicting views with justifiable options. Beyond the patient dying, is it morally justifiable to retrieve the organs from an anencephalic newborn? These questions will be answered to the best ability of the medical ethics framework, legal options, and best interests of the child. Biologically, a newborn anencephalic child is still a living breathing human being and is seen as a living patient until death is pronounced by brain stem death, or cardiac death which in most cases organ retrieval cannot be obtained because most organs cannot survive the wait of death from this disease.[81]

First let's consider the anencephalic infant and the mother's choices during this considerably rare and difficult case. The anencephalic disease should be talked about in grave importance with the family of the baby before the baby is born. These discussions should include the details about the disease, what it entails, physicality, psychosis, functionality, and what the baby will need when born. The prenatal detection of this disease is almost one hundred percent possible in most cases during the first and second trimesters.[82] Informing the parents of these anomalies, survival chances, description of operations, recovery process, and survival rate in terms of quality of life for the patients best interest helps weigh the options prior to birth, and educates the parents as to the potential brain functionality possible and expected poor prognosis before the baby is born.[83]

The mother had informed information of her baby having anencephaly prior to her baby being born, and still continued the pregnancy as planned. The mother believed that a human life is a human life and all life has value. This is most religious backgrounds belief to continue with life support until God takes the child. Baby K's mother is within her right to demand life-sustaining treatment for her baby based upon moral and religious convictions, however, if her baby were to be considered a futility case after brief ventilation because of the underlying

anencephalic disease, then life sustaining treatment would only prolong dying which may not be in the best interests of the child rather than the parent.[84] This is not uncommon and could be considered a feasible option at the time of birth until the physicians have confirmed the anencephalic deficits in Baby K. Representation of multiple specialty disciplines would need to be considered in order to move forward with possible ethically permissible actions.[85]

On the medical side, the physicians may see this disease as medically futile because there is no cure. When the alternative of any treatment option placed for an anencephalic child is death, the question does not turn to what treatment plan is best for the child rather than what values and ethical support for a quality of life or best interests of the child is condoned.[86] Having the child be delivered to and from the hospital over the course of two years because of trouble breathing, cardiac arrest, or system failure does not seem fair to do aggressive treatments when the baby has an incurable disease to which it would need to be shocked, defibrillated, and ventilated multiple times throughout the short course of life. However, the same notion is to say that the quality of Baby K's life does not seem so unreasonable to continue life because the baby does not have sensation of pain, abuse, or neglect.[87] The options that need to be balanced in this short life should be decided based on the benefits and burdens to the infant.[88]

There is no cure for anencephaly. When a patient is going to die no matter what science and medicine has evolved into, prolonging a person's death may be ethically permissible in certain situations. In most cases, the parents are emotionally dealing with having a baby and now having to cope with the fact that their new born child is dying. Religious convictions can also be hard to tackle. The child does not have the same convictions as the mother because they are not old enough to comprehend them. This can relate to Jehovah Witness because the child will receive blood until they insist that their conviction of this religion meets their same values at

heart. Therefore, the standard of practice is to do what is in the best interests of the child, which in a case where prolonging life may lead to suffering in a sense, the course of action may in fact be to discontinue life sustaining treatment, provide the best religious support possible for the family, and be there for the infant in their death.[89]

The issue of organ donation from anencephalic patients derives from the possibility of using a dying patient's organs as a means to benefit another person for good. The council on ethical and judicial affairs insists that organ retrieval for anencephalic children is illegal before the infant's death.[90] Anencephalic children are still human lives, and should not be seen as a vessel of organs that could be obtained before death. On the other hand, once a child is brain dead, the organs can be harvested just like any other adult patient, and they can be kept on a ventilator support until the organs can be retrieved. Ideally, it would be resourceful to use organs from anencephalic newborns, but their death should be dignified and justified before any thoughts of viable organ donation takes place. Understand under present laws and ethical considerations, organs cannot be retrieved if it is to prolong life because of the possibility of viable organs and especially if we treat the child differently for the only reason of organ procurement.[91]

Department of Health and Human Services developed a law to protect handicapped newborns named the Baby Doe Law, which states that medical teams cannot withhold life sustaining treatment unless newborns meet the following three criteria: the infant is irreversibly comatose, treatment would only prolong dying, and treatment would be futile in terms of survival.[92] Medically unstable newborns that fit this criteria should prompt physicians to not even offer life sustaining treatment when these children are this severely forgone. This takes the stressful task of deciding to try aggressive treatment or end the life of their baby away from the

parents and allow them to just be with their child at the end of their life. When an aggressive

treatment request is made for a patient that seems medically inappropriate, an ethics consultation

should be placed.[93] The issues that have fallen to raise ethical questioning was critically circled

around withdrawing, withholding, and futile treatment for anencephalic newborns. This also

points to the dilemmas of moral distress for medical teams during a time where they believe

treatment is medically inappropriate. Ethics consultants should maintain good communication,

continue discussions with family and medical team to resolve the conflicts at hand.[94]

In most cases, families will come to accept the removal of futile treatments if good

communication is fostered, involvement of continuous support and the resolve of conflicting

problems at hand. There is no cure for anencephaly, but healthcare providers and ethicists should

play a critical role to inform the parents of the child about the disease at hand, educate the

physicians about possible avenues if the parents choose to continue pregnancy, and also

proactively help define standards of medical care for anencephalic infants which may discourage

aggressive medical care.[95]

<u>III. Neonates: Genetic Testing & Stem Cell Treatments:</u>

This Chapter will discuss genetics and culture change, genetic screening and gene

therapy, ethics consultations to resolve the knowledge gap in genetic screening, stem cell

treatment, and ethics consultations to educate society to prevent societal consequences.

<u>III.A. Neonatal Genetic Testing:</u>

Genetic testing in neonates mainly comprises of genetic screening, gene therapy, and

stem cell treatment. These tests play a role in long term decisions for families with children that

have disabilities or chronic diseases. Genetic technology can now determine these events at an

early stage of life that allows for parents to choose the best route of care or prevention for the

best interests of their child. Genetics now can provide healthier and safer health abnormalities

for neonates due to early diagnosis and treatment plans. This section will go into detail about each genetic test and the positives and negatives of each testing for the best interest of the child and parent.

<u>III.a.i. Genetics and Culture Change:</u>

Genetics is not just a science, but it is becoming a way of thinking in the sense that people see life through a discourse of heritability and gene action.[96] This perception is seeing the world as gene manipulation, therapy, treatment, and occurrence. Most of genetics is dedicated to disease prevention, and may have no therapeutic benefit when conducting genetic research.[97] Genetics in medicine, at least in this case, is allowing parents of a child to be aware of the genetic traits the child may hold when they are born. These genetic tests medicalize their child's gene infrastructure at an early stage to identify traits that may be a harmful undesired trait.

Human evolution has evolved to show natural selection of genomes over the past thousand years, as an adaption to the cultural change and environmental conditions.[98] The conditions and changes in society's views have progressed genetic infrastructure in a new direction that now is bonded to the cultural change in society. Public culture however, does shape societies views on the understanding of genetics.[99] The understanding of genetics in medicine can be foreseen through society's views and opinions on the matter and how culture foresees genetics in the future. Society's culture has ramped up evolution by reshaping the material world.[100]

Humans have a natural wondering or curiosity. Genetics allows for curiosity to have factual results that can be implanted in the human genome to change the course of disease related alleles. Parents may want the results of a genetic exam, but may have to carry the disruption of the child's life as a burden.[101] This means that a parent can obtain the results of a genetic exam,

but may have to live with the choice of what to do with the material of the exam. This could lead to genetic manipulation of genes, abortions, non-quality of life, or a difficult life. The choice to know the answers of genetic tests are a frightening conclusion.[102] Cultural evolution has made it easier for parents to find out the genes of their un-born baby, but all testing can come with consequences.

The new age popular mindset about genetics is that genetic testing widens the gap on human disabilities creating a basis for the discriminatory nature of diseases or disabilities based upon sorting people on their genetic deformities.[103] Most people requesting genetic testing are white, middle to upper class, and highly educated individuals which already extend the inequalities in services sought and widen the inequality gap.[104] These tests can contribute to widen the societal gap in class which already exists. More people with higher socio-economic status are more likely than others to take advantage of genetic testing which can be worrisome for future generations to have the lower social classes be considered a mark of genetic disabilities.[105] These concerns are fallible considering access to genetic healthcare is mainly tailored to upper middle class citizens. Genetic testing should be open to all individuals as the responsibility lies with each genetic partnership interested in knowing the genetic anomalies in their newborn.

Society is putting the evolution responsibility on the individuals having a baby to prevent suffering for future humans.[106] These new societal norms have been reevaluated by the cultural norms by the principle of autonomy leading the forefront of these individualized responsibilities. People can decide for themselves what medical knowledge they want to have available for the future of their children. The responsibility now rests on the individual to allow their child to live

a "better" life than what it is sought to be previous the medical genetic testing. The challenge is for people to reflect on their current decisions for the future of evolution of human life.[107]

The future will include adaptability in which people will need to be proactive in anticipating environmental trends to develop a greater sense of the populations' social responsibility.[108] Population accountability will be crucial for ensuring an ethical framework for genetic screening for future treatment plans.   The culture of the human race is to envelop change, and to conquer knowledge to develop genetic ideas that surpass the current environment of human kind. As the world becomes more and more advanced, knowledge will change and facilitate growth to expand genetic phenomena's.[109]

III.a.ii. Genetic Screening and Gene Therapy:

Genetic screening is the search for a healthy person through: screening their genes for predispositions to certain diseases, possible lead diseases through their descendants, or produce other factors not known for disease but other relative problems.[110] This new age science can allow for parents to protect their children against strains in their known genetic makeup from their ancestral history. Genetic screening then can produce offspring with healthier outcomes in life due to early diagnosis.

The first true new born screening began in the early 1960's with a heel stick that now screens for more than fifty conditions.[111] These conditions screened are chosen neurologic deformities, muscular deformities, chronic illnesses, or certain disabling syndromes. Almost all states in the United States have educational material for parents and or the general public on genetic screening.[112] Information on genetic screening is available to parents and or people seeking to have a genetic screening after birth. The heel stick is now considered a routine screening or a standard of care so consequently the procedure does not need an informed consent

obtained.[113] Genetic screening can provide necessary genetic qualities that parents may need to obtain in order to have the best treatment plans for their child that may have some disorder. However, policy makers have acquired burden to determine which disorders or diseases should be considered mandatory genetic screenings.[114]

Much of the genetic screenings in newborns are now mandated in the United States because when they cannot speak for themselves, physicians will take on the responsibility to do what is best for their patient.[115] This test poses healthier outcomes; however, this screening also is made into an obligation by the state. Many of which, consider most mandated policies to conflict with basic human rights to choose what they want done with their body. These conflicting views are both important in their own positions as to advance health in people by advancing medicine and to not waver in their own personal moral convictions of their child's body.

However, the parent of the child who will be genetically screened has the right to not know the results and or participates in the confidentiality agreement.[116] So, reasonably the parent can agree to the mandated screening to better further their child's best interests as well as adhere to their own personal moral convictions by not acknowledging the test results. Both the parent and child's confidentiality will then be safeguarded by physician patient protocol and the parent and child can both get the care best suited for their needs.

Gene therapy is the therapy in which separate genes are implanted in a patient's body to obtain a therapeutic outcome.[117] In other words, the introduction of a genetic element into a person's gene set to alter the disorder in a form of treatment.[118] Gene therapy is an additional step to gene screening. Screening diagnoses the problem, and gene therapy is able to treat the problem. The abnormalities in genes are then caught at an early stage which can be treatable.

Gene therapy may be more successful in newborns than in older children or adults speaking to the fact that it is likely to provide early intervention for urea cycle defects, lysomal storage diseases, cystic fibrosis, muscular dystrophy, and other neurodegenerative disorders.[119]

This process, unlike gene screening is invasive and more complex. In SCIDS disorders, the ADA genotype of the enzyme is incapable of carrying out normal immunologic responses, but with gene therapy, they can harvest a normal ADA gene and implant it within the bone marrow of the patient in order for it to transmit normal ADA genes throughout the Tcells making the disease "curable".[120] Medicine is able to cure unwarranted diseases or syndromes by creating and rewiring genes in order to form a healthier human being. The success of gene therapy is dependent on the vehicle or trajectory used to target the cells with minimal toxicity, which non-viral gene therapy is a working progress that will rely on the better understanding of the gene transfer system.[121]

The key question that needs to be asked is should these tests be done?[122] The reason this question stands out ethically is because not every disease or gene mutation causes this unbearable burden to every person's life. Each human being sees their quality of life uniquely. Therefore, a parent may be asked to have their genes screened, but they should also be asked if they want their genes altered. New born screening is rapid and identifies few genetic disorders which effective treatment and inexpensive tests exist.[123]

III.a.iii. Ethics Consultations to Resolve the Knowledge Gap in Genetic Screening:

There is an increased need for genetic counseling services and a growing realization that the services rendered are in dire need of optimal methods that produce a better genetic counseling service.[124] Genetic counseling services are currently limited or unheard of because most genetic physicians, psychologists, geneticists, or pediatric specialists take lead roles in

informing their patients' about their genetic makeup and their baby. This paternalistic physician-patient relationship hinders the undisputed knowledge gain that could be obtained if patients' received unbiased, non-clinical information to be informed about their genetic situation. The national genetics foundation provides a referral service and a reference network that inquires more than fifty counseling clinics across the nation, however, an alternative option that should be explored more is developing a program specifically for a professional genetic counselor.[125]

In 2003, the national society genetic counselors, NSGC, offered the definition of genetic counseling as helping people understand and adapt to the medical, psychological and familial implications of genetic disease alongside ethical practice.[126] This definition however, falters due to the fact that unless an individual is educated in the realm of medicine, psychology, ethics, and family counseling they are not qualified to give advice or information pertaining to genetic testing.   Neither realm of education provides certainty of professional genetic counselors because the basis of genetics is based upon probabilities not certainties. The professional realm of genetics correlates with uncertainties as the norm to which dominance of autonomy and contemporary medical ethics will help their clients arrive at the best decisions for their own personal gain.[127]

The aim of genetic counseling is to inform the patient of genetic risks in their offspring or other family members and by doing genetic tests they are able to reduce the potential risk.[128] If genetic counseling is applicable in a way that counselors can ensure patients' of risks, benefits, and alternatives of treatment options after receiving genetic mutation confirmations in a way that they can understand then proceeding with genetic testing would be ethical. Genetic counseling should encompasses a communication process that tries to ensure: the comprehension of medical facts, diagnosis, course of the disorder, management of the disorder, heredity of the disorder,

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alternatives to prevent the reoccurrence and decide which course of action aligns best with their values, goals, and religious standards.[129]

Approaches to genetic counseling have styles of communication based upon directive or non-directive approaches that in either case judge the counselee on their needs and reflectively choose the style of communication to document emotional understanding, and information adherence.[130] Directive communication may come off as biased in some situations, and may add the physician's opinion as to what the patient should do in a particular medical situation. A non-directive approach allows for a more positive approach eliciting the patient's values and goals at the forefront of the conversation and requires patient understanding to make an informed decision with no bias that coincides with their moral convictions. Either approach whether directive or non-directive may emphasize the counselor's background or personal beliefs, however, seeking multiple counselors or alternative options develops patient autonomy to make informed decisions.[131]

No matter the clinical benefit to the patient or baby involved in the genetic case, all information including psychological and social risks should be disclosed.[132] A genetic counseling session should then draw out the patient's short and long term goals to clarify patient values, improve communication, encourage educating the patient on the genetic situation, and speak to the patient as a person not a geneticist.[133]

The practice definition of genetic counseling has changed and now reflects a larger scale of social trends, socioeconomic backgrounds, medical technology, scientific knowledge, and changing ethical framework and values.[134] Implementing clinical ethics consultation services alongside genetic physicians or professionals trained in genetics will help to better communication and knowledge gaps during the initiation of genetic testing. No genetic

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counselor can know every branch of medicine nor every diagnosis expertise to deal with all the cases involved in genetic counseling.[135] Clinical ethics needs to be a part of genetic testing alongside specialized medical personnel to breakdown the diagnosis in a non-medicalized manner as well as assuring proper unbiased informed decision making between patient and physician. Genetic counseling has turned into a team affair which cannot be done without a variety of specialists available to explain different aspects of the genetic process to further congruent care.[136]

III.B. Stem Cell Treatment:

This section will define stem cell treatment and how ethics consultations can educate society about the slippery slope or consequences of promoting science to change human norms.

III.b.i. Stem Cell Treatment Defined:

Stem cells are a group of cells that are capable of renewal and replacement of different types of tissues that can offer alternative therapy options to benefit the course of potential diseases.[137] These cells can change the course of disease by offering healthy replacement cells that do not carry the disease within their DNA. These cells have the potential to dominate chronic disease ridden cells and transform heredity prone diseases from parent to child. The pluripotent stem cell lines can actually match a persons' nuclear DNA to eradicate specific diseases by screening in advance for potential new therapies since these type of cells can differentiate into an array of specialized cells.[138]

Neonatal brain injury usually requires stem cell therapy such as hypoxic neonates or ischemia that may be common in hemorrhage, stroke or asphyxia neonate patients.[139] These patients such as anencephalic patients are neonates born with a brain injury effecting part of a neonates brain that is more than likely not reparable. Prenatal diagnostic procedures have been

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developed to detect birth defects in utero which include, but are not limited to: maternal serum screening for alpha fetoprotein, human chronic gonadotropin, and unconjugated estriol, amniocentesis, chronic villus sampling, and ultrasonography.[140] These types of cerebral stem cells affect the central nervous system which can in turn help the system with defects with early diagnosis, prevention, and treatment. Stem cells give rise to three cerebral types of cells: namely neurons, astrocytes and oligodendrocytes which are mainly taken from bone marrow and recently cord blood that are delivered through the vascular system or locally to the brain.[141]

The main ethical concern of human stem cell research and therapy is how the cells will be involved in research and how they are derived.[142] Pro-life supporters have had decades of debate on whether it is appropriate to use stem cell research on aborted babies or from IVF procedures. These supporters are against stem cell therapies because of the indication when a baby or group of cells are considered alive and an understanding of the gestation process of viability outside of the mothers' womb. Ethical debates about solely creating life for research has existed since the beginning of embryonic research, however, we should not destroy left over IVF embryos if the ethically acceptable goal is to treat disease and justify saving lives by informed decisions.[143]

Decisions that concern the termination of the pregnancy should be made by the mother and partner, but not because the healthcare provider paternalistically gave their opinions of the situation.[144] The parents have the right to choose for the best interests of their child, but should not be influenced by their physician's sociological position because they have the autonomous human right to choose. Great good is unjustified if it comes at the price of violating human rights which could lead to destruction of embryos through stem cell research, embryo farms, and cloned babies or uses of fetuses for spare parts, or even the commodification of human life.[145]

However a parent chooses to embellish their child's life or prognosis should be their own purgative if the best interests of the child are in the forefront of care. Ethical guidelines should put special emphasis on the informed consent process in stem cell based research or stem cell therapy facilitating the elicit unpredictable risks based upon unknown effects.[146] Informed consent always plays a crucial role in genetic control of human malformations or chronic disease opportunity. Parents and physicians want what is best for the child at hand, but without proper knowledge of the medical situation and risks either parent or physician can be blinded by paternalistic thoughts. The most important verification of crucial ethical concern involves the informed consent process and disclosure of pertinent information to not mislead patients' into a therapeutic misconception if therapy does not change the genetic situation.[147]

Most cases, there is a difference between serious and not serious genetic disorders. Most people find that hospital ethics committees, physicians, and groups should not decide whether a condition is serious or not serious, but the parents of the child should decide based on the child's individual medical situation.[148] Healthcare professionals should focus on the detection of fetal abnormality, treatment options, how to counsel their patient and family, and to what effects will this counseling entail.[149] Parents should look at the medical situation from the child's perspective and quality of life. Physicians should diagnose, treat, and provide options of care for the child patient. As far as American geneticists, they generally oppose the idea of having a list of diseases or syndromes that are termed serious or not serious because this imposes the limits of autonomy and the rights of patient and or medical professionals along with the principle of justice.[150]

III.b.ii. Syndromes and Diseases with Effective Early Treatment Plans:

Many chronic illnesses that encapsulate the lives of newborns can be prevented or managed by early detection. Maple syrup urine disease, Streptococcal disease, Down's syndrome, congenital heart defects, and Cystic fibrosis all are major chronic illnesses that without treatment can shorten the lifespan of a newborn child. A research study was performed to show cost effective interventions for the most lifesaving preventions and if these interventions are done at an early stage, forty one to seventy two percent of neonatal deaths could be averted across seventy five countries.[151]

Maple syrup urine disease, or MSUD, is caused by an inherited deficiency in two oxisiocaproic acid chains that exert neurotoxins causing acute and chronic brain dysfunctions that can rapidly progress into a coma state and without rapid removal of the affected chain the newborn will have brain damage.[152] This disease if not caught at an early stage, can be more life debilitating than some other chronic diseases. Early and effective treatment is optimal in the case of MSUD. The early diagnosis from pre-genetic screening combined with aggressive treatment will produce the best possible outcome for the unborn to newborn child.[153]

A study was done on six hundred thousand new borns to find out whether genetic screening for Streptococcal disease was more effective than no screening and it was proven that it was fifty percent more effective in preventing early onset disease which can also warrant the consideration of universal preventative screening.[154] This disease otherwise known as strep throat is an infectious bacteria build up in the newborns throat. In the United States, this infection still causes approximately sixteen hundred illnesses and eighty deaths per year in infants and if they do survive the infection may cause developmental disabilities, mental retardation, hearing, or vision loss.[155]

Down's syndrome affects the twenty first chromosome and without early pregnancy screening or blood test this type of syndrome will go undetected. Soon after birth, children with this syndrome should be assessed for congenital heart disease, hearing loss, opthomalogical problems, and obesity because of low metabolic rates, lower bone densities, skin problems, and hypothyroidism.[156] Children can live with this syndrome; however, if parents are not properly advised or informed of the lifelong ailments or medical anomalies then they will be ill prepared for their life with a Down's syndrome child. Different disciplines, geneticists, and physician specialists should counsel parents about a child with Down's syndromes and discuss prenatal screening, newborn diagnostic testing, health issues, advocacy groups, educational choices, and transitions for adult living.[157]

Sometimes, even though there is genetic screening and gene therapy, technology may still not be able to diagnosis certain diseases, defects, infections, or syndromes. Congenital heart defects vary in appearance at different stages of pregnancy, and a normal heart at gestation does not exclude a severe heart malformation at birth.[158] Echocardiography should be done throughout the pregnancy in order to detect these malformations in the heart at an early stage in pregnancy. This type of precautionary measure may become a standard in prenatal screening, but for now it is only used in detected heart defects. Parents should be aware that these diagnostic tests are necessary for the proper treatment plan before the birth of their child.

Lastly, cystic fibrosis is another common inheritable disease that without treatment most patients with this disease will die at a young age.[159] This disease effects the respiratory system of a person and without genetic screening of this disease, children are more prone to have a harmful and aggressive deterioration of their respiratory system. Screening of this disease usually guarantees a ninety four percent survival rate, rather than not being screened which

results in a high mortality rate among infants in their first years of life.[160] This disease does have a treatment plan, and a very successful life expectancy rate, but only if genetic screening is done properly and an effective treatment plan is put into action. Most of these diseases if not preventable, are treatable with genetic testing, screening or therapy. Catching the diagnosis is the initial step to livable quality of life chronic diseases.

The American Academy of Pediatrics recommends preventative pediatric healthcare by: obtaining the history of the patient and family, measurements, sensory screening, developmental/behavioral assessment, physical examination, and oral health from infancy through adolescence.[161] This standard of care should be a guideline throughout a child's pediatric care to therefore ensure preventative healthcare to the best of medicine's ability for the child patient. The more medical professionals are comprehensive in their various examinations of the child at early stages of life then the more effective, organized, and successful the treatment process of medical care to the child patient is.[162]

Currently, researchers are working to develop personalized medicine that involves the individual's personal genetic makeup and microbiome to specifically treat the individual's medical needs.[163] Personalized medicine is only plausible if medical research is formed from an extensively large population. Without the diverse genetic data from differing environments, personalized medicine will cease to exist. This new science could change health for future generations, but ethical implications will lie at every stage of the on-going research endeavor. The more ethical concern for microbiome mapping studies will be compensation to all ethnic representation, cultural diversities, and socioeconomic groups represented in the study.[164]

III.b.iii. Ethics Consultations to Educate Society to Prevent Societal Consequences:

While genetics triggers most alterations in humans, as much as ninety nine percent of our DNA is shared with one another, yet at the same time, we are all individually diverse.[165] Diversity between humans is a unique trait that allows for individuality, different traits, physicality, and knowledge. Biodiversity is linked to the ecosystem we live in which is stable to the extent that our population is diverse, but if our ecosystem changes by culture, intellect, aesthetic, or spiritual means then this can alter the species within our ecosystem.[166]

Medicalization of genetics is sought to abstract normalcy and transform norms into abnormal spheres.[167] This means, views we currently see as normal in genetics can become distorted in the future.   This may in fact change our ecosystem in which we currently live in, and acquire a new "normal" system that shares new aspects of uniqueness to new genetic anomalies. This new environment that we will live in will possess the new heredity traits of individualized genetic changes from genetic testing. In turn, the parallels between education and genetics are that if people are adequately educated and understand certain elements of genetics within social values, religious contexts, risks, ideas of culture, and trust in science then they can see without questioning the fundamental reasons for regulatory genetic testing reinterpreted in their own way.[168]

Public education in genetics seems to be essential to form a basic understanding of genetic testing processes and public policy in order to give adequate informed consent.[169] Education will provide individuals in non-clinical settings with information to ask more informed questions about genetic testing prior to information gained. Individuals' can be more involved in their care if they have the basic simplistic information and knowledge of genetic testing available prior to their physician genetic testing meeting. People who are not physicians

such as ethics consultants can provide important insights of the implication of non-informed healthcare decisions, offer guidance, and help resolve difficult decisions.[170]

Genetics should not only be education to non-healthcare professionals, but to residents and incoming healthcare professionals. This approach can close the gap of non-educated professionals in genetics alongside understanding the possible implications of genetics if society is ill prepared. An American task force conditioned a study about genetics in medical schools only to sadly find out that the teaching of human genetics in North American schools was nearly nonexistent and at the end of the study set out tasks to encourage evaluations of effectiveness of efforts for educators to improve genetic teaching for future institutions.[171]

Genetics, even when it can open new doors to change the face of disease, it can also cause societal consequences. The new genetics is in an age that health policy will be enacted with or without societal input. Society needs to be aware of the implications of genetic policies that may be indorsed involving privacy, autonomy, and discrimination. Third parties may demand genetic testing or access to genetic information which causes privacy concerns and loss of control over their bodies by discriminating through health insurance.[172]

Clinical ethics consultations would oversee genetic testing in the event that patients' are not well educated in genetics, need a risk benefit analysis, or require a stronger informed consent process to determine knowledge on the genetic endeavor they are about to embark on. This ethics consult will provide a higher quality of care for the new age of genetics. Educating society and healthcare professionals about genetics will decrease societal consequences and increase the ethical, more informed, quality genetic testing. Clinical ethics consultations support geneticists, counsellors, and patients to help them resolve tough medical decisions which they may have to deal with in their daily lives or in the lives of their future children.[173]

Genetic discrimination, and changes in biodiversity pose possible threats for the future of our society. Careful policy changes along with educating our population will help progress society's understanding of genetics into the new age because without these changes there may be unethical downfalls. Ethics consultations can be a positive influence during regulation of policy, and pursuing equal opportunity for genetic testing while providing ethical genetic practice in future medicine. Proceeding forward in genetics, we need to be cautious about societal implications and ethical issues for democracy of all people be treated equally despite all of our differences.[174]

IV. Conclusion:

Ethical conflict in the clinical setting has always been a problem, but now we are striving for high quality healthcare that prompts clinical ethics consultants to be a part of conflicting medical situations. Clinical ethics consultations can be done in a variety of ways, and depending on the healthcare system and the specific ethical dilemma each case may need a different approach. The formation of clinical ethicists in the medical field of pediatrics not only encourages a higher quality of care, but addresses the moral issues that parents and or physicians are having about the care of the pediatric patient.

Genetic testing has stormed the front doors of medicine within the last couple decades. It will not stop now, and will only keep upgrading, revising, and remapping the genetic future. With careful planning, genetic testing can change disease, therapies, and culture of society. Genetic screening and therapies such as stem cell treatment may change chronic disease as a concept of the past. Ethically, there is a duty to the patient embarking on the genetic endeavor to have all pertinent information, disclosure of genomic risks, and a clear understanding of the potential for failure. Genetic mutations to cure disease ridden cells for future generations is quite

possible. However, without a close eye, the storm may grow bigger and faster than all of us.

Ethical implications of genetics grow with every new genetic endeavor. Society and ethicists

should be a part of the change in health policy to ensure democratic ethical rights. Science and

medical knowledge are currently not reflected in the education of non-healthcare citizens or

rightly taught for medical students. Each area of genetic knowledge should be assessed and

addressed in terms of genetic attestation. Clinical ethics consultations should be implemented

into policy, knowledge lending, and pre-genetic testing experiences. This service will prevail in

quality ethical genetics for future generations to come.

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Chapter 6: Ethics Consultation Quality in the Research Setting of Pediatric Medicine:

This essay will discuss the ethical problems in medical research imposed upon vulnerable populations. Medical research should uphold the respect for all human beings whether or not they are a child or adult. This chapter will introduce international research considerations including cultural diversity, human vulnerability, and benefit sharing. This is presented in section one through the development of global bioethics seen through the principles, human rights, and ethical framework. Medical research in pediatrics is an arduous task for all that are involved. Ethical frameworks, systems, protocols, and consultants should embody the ethical standards and principles set forth by ethics in society to produce the highest level of quality research pertaining to pediatric medicine. Ethics consultations in particular will be able to perform clinical consults in pediatric research that will enable the research participant and family members to feel assurance when beginning, developing, and succeeding in the research endeavor.

There is a developing need for a quality ethics consultation in medical research pertaining to pediatric medicine. When a physician initiates medical research with a child patient, the standard of care versus research options should be explained in a way that there is no therapeutic misconception between treatment versus medical research trials. This is where the minimum harm criterion factor comes into play to which the harm done to the patient, which should be minimal at most, should only come at the acceptance of the child patient. All of these factors in pediatric research involve informed consent, autonomy, and risk/benefit analysis. Each of these particular topics need to be of the utmost importance when conducting ethical research in pediatrics. Ethics consultations will provide a stronger framework to assure safeguards of approval, communicating standard of care versus medical research trials, and institute informed

consent during a risk/benefit analysis. Clinical ethics consultations can indefinitely bring higher quality patient care in medical research pertaining to pediatrics.

II. Protecting Human Subjects: Global Perspectives:

This section will discuss cultural diversity, human vulnerability, benefit sharing, principles of bioethics, human rights, and universal ethical framework.

II.A. Research & Multi-Cultural Society:

In vulnerable populations there is much cultural diversity that one needs to be aware of when conducting medical research. Developed countries' medical research on vulnerable populations should not disrupt their cultural diversity, or the vulnerability of the population. These factors play a part in benefit sharing. The people of different backgrounds need to benefit just as much as the people conducting the research. Researchers need to understand that their actions can have consequences, and they need to respect, honor, and understand the population they are controlling as their research subjects. This section will discuss cultural diversity, human vulnerability, and benefit sharing in order to better understand the need for quality ethics consultations for vulnerable populations.

II.a.i. Cultural Diversity:

Cultural diversity spans more than the variety of culture in different areas of the world. Cultural diversity includes all the areas of bioethics. Autonomy and informed consent are main factors in medical research. A physician or researcher needs to obtain this consent to proceed with their research. There may be cultural differences to be considered in order to acquire the patient's informed consent. Cultural diversity includes the concept of informed consent. There is a challenge to develop a global culture in medical treatment and research that insures the patient to be respected.[1] The reason this is difficult to understand is because every culture has different forms of respect.

Translators may also need to be involved in the discussion of informed consent. A translator creates some ethical issues whether the patient or subject fully understands the translation, the precision of the translation, and the confidentiality of the information given.[2] The medical information translated diverse speaking populations may not be understood in the rural areas of underdeveloped countries. People may have less education, and be less aware of what they are truly consenting to.   The language barrier alone is a difficult obstacle to overcome. Then there is the relevance to make sure that the subject or patient understands what they are about to consent to. Consent of an autonomous person in a less educated population must be made clear to the best of their knowledge. The cultural diversity and understanding of the population are complicated, but the ethical aspect of this all is that the people need to truly understand and be able to give fully informed consent to the medical research upon which they are about to embark.

Cultural diversity is an ethical essential, undividable from respect for human dignity.[3] The respect for human culture and dignity ought to go hand in hand. These two concepts cannot be ignored. Human dignity is a part of every human being no matter what area of the world into which they were born. The respect for a human person should be a globally-known moral principle. This should never be thought to be a deterrent in medical research.

Medical research focusing on a human subject can be a controversial issue. There is a vulnerability in culturally diverse populations. Certain populations, such as racial minorities, economically disadvantaged, and the very sick, are potentially sought out to be research subjects.[4] These people are in vulnerable states that will tend to agree to anything in order for a possible end to their illness or economic conditions. With these vulnerabilities in play, many individuals can be taken advantage of. However, the principal of vulnerability demands the

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acknowledgment of exercising the right of autonomy, and the giving of consent does not eradicate the vulnerability which cunningly gives way to exploitation through hopeful presentations of clinical trials.[5] No matter how appealing medical research may seem, it is important to consider the population and understand no matter the cultural diversity, or vulnerability of the population, the same standards of ethical medical research should be upheld across the globe.

II.a.ii. Human Vulnerability:

Vulnerability is defined as the exposure of being wounded.[6] Vulnerability spans across all of human kind. Every human being can be vulnerable at some point in their lifetime. Human vulnerability is no longer based upon specific rights rather the obligations that are due to freedoms of the individual developed by autonomy and ethics based on the responsibility of brotherhood.[7] These freedoms are owed to every individual. Vulnerability is inherent to all human beings. The freedoms that each individual possesses should be a right and taking unjust advantage of any human being's vulnerability must not be trivialized.

Human vulnerability is more prone in less developed countries because of the susceptibility of being poor, uneducated, and opportunity to thrive. Advantaged people of developed countries should not pray on the weak and vulnerable in order to achieve certain goals. There should not be a loss of sight of the individual patient, whose life, safety and health is of utmost importance.[8] The vulnerable have the right to refuse treatment and exercise their right to express their best interests.[9] Their interests may be different from the interests of other people from differing countries. The obligation is to the individual patient who will either participate in the research study or decide to decline, depending on local morals and values.

Awareness of the vulnerability of human beings is important. It is easy to take advantage of vulnerable people to get something that someone else wants. People can prey on vulnerable people, in this case, to achieve medical research productivity. Respect for human vulnerability requires the protection against being wounded and the respect of integrity so that the individual is not reduced to a mere nonexistence.[10] These people are preyed upon because they are vulnerable and exposed. Unscrupulous people will take unjust advantage of this population of people who can easily be overthrown in respect to their integrity and vulnerability. There needs to be protection for these people. They need someone or something to acknowledge their existence, and respect their culture, diversity, integrity, autonomy, and what little choice they have.

The needs of these economically deprived people need to be recognized. The understanding of these people is important in order to align the research safeguards within our own society. Defining these people as vulnerable implies the obligation to protect them and insure their safety.[11] It is a duty for all mankind to protect the value of humankind and not diminish another human being's self-respect only because of the locale of where that person was born and raised. The UNESCO document is determined to protect the dignity and respect of human beings, without discrimination, when dealing with biology and medicine.[12]

II.a.iii. Benefit Sharing:

Benefit sharing is the use of sharing benefits of resources to benefit all of humanity and not just a certain collection of people. This principle involves the concept of benefit and harm. There should be a maximization of benefits and a minimization of harms of patients or research subjects whose interests outweigh the interests of society.[13] This way biological diseases and harms of society do not take precedent over an individual or group of humans' well-being.

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Benefits consist of: advancing the patient's interests, producing new knowledge of value to future patients, or devising a policy which advances common good.[14] A person should never enter into a research study where they are considered only a subject and not of value. Their interests, understanding, and knowledge of the research should be important to the researcher. The research should always advance medical research and should allow not only the individual researcher to continue, but to allow all medical research to thrive. It must be shared with the universe. Harms may be financial, physical, emotional, or spiritual, either posed one at a time or all together.[15] These harms violate a human being. Imposing one of these harms on a person violates their human right, respect, dignity, and integrity. Ethics safeguards make sure that benefits outweigh the risks.

Poorly designed research will bring little to no benefit to humanity, and needless risk or harm to individuals involved.[16] The research must allow benefit to all persons involved in the research study. The fair choice of all experimental subjects should be chosen on a fair basis to prevent harms and exploitation for benefits.[17] All of humanity depends on the future research of scientists, researchers and physicians.

The concept of benefit and harm promote the concepts of beneficence and non-maleficence into play. Non-maleficence is the duty not to inflict harm.[18] Beneficence is to do well by someone. These two concepts are a part of every research study. The researcher, physician and those directly involved in the study should always do what is right and not inflict intentional harm to the patient. These people accepting the research trials intend a good outcome and that can only happen if the physician is beneficent and non-maleficent. Only the human race has the ability to act to do direct good or to do harm.[19] There is a choice and the benefit should outweigh the ability to do harm.

The research should benefit the individual specifically.[20] In addition to individual benefit, the research may also impact all of human kind. Benefit and harm is a difficult issue to address. The researcher looks for benefits to their research and the individual looks for benefits for themselves. It is up to the ethics of research to configure safeguards and ethics framework in order to conduct beneficial research to not only the individual, but both parties involved.

II.B. International Research Ethics:

Global bioethics has become pronounced and encouraged, both methodically and systematically through the principles of bioethics and the framework of universal ethics. The standard principles of bioethics are gradually being applied globally across all humankind. When these principles are applied, and positive results prove them to be advisable, there is a certain ethical framework that is built to sustain the ethical issues in different areas of the world. In order to correlate pediatric ethics research, one first needs to understand international ethics framework, because all human rights, bioethics framework and international correlations apply.

II.b.i. Principles of Bioethics:

Global bioethics is a simple breakdown of bioethics, but in a universal presence. This concept is meant to adopt bioethics globally in order for all of humanity to obtain their basic principles. These principles include: autonomy, beneficence, and justice. The presentation of these principles create underlying factors such as: informed consent, risk/benefit assessment, and a just selection of subjects for research.[21] Autonomy is the capacity to reason and the freedom to choose for oneself.[22] Both need to be present in order for someone to act autonomously.[23]

Informed consent and risk/benefit assessment may also be involved. These two principles coexist with autonomy because all patients or research subjects have personal freedom and adjoined will. Informed consent allows a person to consent to surgery, treatment, or medical

research with their own free will. The patient must be both competent and aware of the procedure to which they are agreeing. In order to understand the information given to the recipient and in order to obtain appropriate consent, the physician-patient relationship is extremely important. It is imperative that the physician must explain in great detail and in a way a patient can understand what they are accepting in their care. The patient then must be able to trust and rely on their doctor's best medical judgment. Autonomy of the patient then creates the consent to the next decision in care. In Pediatrics, parents usually are the consenters, and the patient uses assent. True consent evaluates the risk involved and the options available in order to exercise one's atomically chosen decision.[24]

Another aspect of consent is to question when someone has given true consent. Some people are poverty stricken and educationally deprived. They have little power to challenge anything during the medical trial when they do not understand the treatment given. Also, these people have no guidance or medical personnel to look to for questions considering their direct needs. The question of assent and consent in pediatrics is whether the family truly understands what they are embarking on and whether they are being taken advantage of while all their focus is on their ill-stricken child. When people live in poverty and when there are economic benefits of entering case studies or other treatment benefits, they are likely to choose to enter the study. This would not necessarily be a true choice; it is more mandatory for them to save their life or loved ones. This aspect of true consent may be hindered in undeveloped countries, or even areas of developed countries because they have a lot to lose if they do not enter in a proposed treatment trial and medical benefits of seeing physicians on a daily basis. True consent is a difficult and a grey area.

Beneficence is the act of "doing good" for a patient, but not only that, the physician must include trusting decisions with an origin of the patient's well-being.[25] This principle goes beyond "doing well" for a patient; there needs to be a relationship that ensures trustworthy communication and understanding of treatment. Informed consent is the choice that a patient can make, and it involves a knowledgeable understanding of the following procedures: the options available, and the possible risks that may be involved.[26] Not only is the aspect of consent involved in medical research, but the idea of "do no harm" which is the doctor's duty to the patient to not put them in jeopardy, even if there is a level of risk involved.[27] The concept of informed consent allows the physicians to bring forward beneficence in which these two concepts go hand in hand. Beneficence is the physician's obligation to include communication, values and wants of the patient in order to respect the patient's well-being.[28] These two principles help obtain guidelines that medical research studies need to follow in order to carry out their learning. The physician must pose a level of understanding and develop a patient relationship in order for their patient to feel at ease when talking about their future endeavors in treatment. This is seen through a physicians' bedside manners. The dialogue with the patient, respect and understanding of their concerns are important in order to understand what the patient is going through. Stepping into their shoes, so to speak, allows the physician to relate and make more quality decision of care. Physicians are urged to respect their patients, attend to education to keep their skills, accept the discipline of their profession and to keep the confidence of their patient.[29]

Justice is the final principle. All human beings deserve the right to human rights, fundamental freedoms and be fully respected.[30] These people, no matter if a minority or a majority, every individual should be considered equal in the respect of freedoms, justice and

dignity. It is a human being's right to be respected in the terms of justice, rights, opportunities, freedoms and obligations.[31] In order to respect justice, each individual needs to respect the above traits of each person. These principles need to be adopted to solve current problems in medical research. These principles also need to be adopted for the sake of equality of humanity and dignity of each individual person.

Justice entails the just responses, treatments, and forgoing actions of the physicians to their patients or in some cases research studies. The most neglected of the three bioethics principles is justice; it is always recognized, but rarely commended.[32] The patient is mainly considered weak and powerless in the hospital. The physician must be able to minimize harm and attend to distributive justice and compensating justice.[33] The act of conversing with the patient on a just level of information will allow the patient to use their atomically chosen choice to create an informed consent. These three principles are the building blocks of bioethics. Physicians, people working in the medical field and patients rely on these concepts to make decisions involving one's health and care.

II.b.ii. Human Rights:

Human rights require three interrelated qualities: rights must be essential in humans; rights must be equal for everyone and rights must be universal.[34] Human rights should be based on the mere fact that everyone is human and should be treated equally.   Human rights also posses the quality that every individual has their own ideas, thoughts, and knowledge to create their own right. Rights remain open to question.[35] Human rights are always changing and they pose the question of who has earned those rights and who deserves them.   This question is still being posed to this day. Human rights should always be questioned when they are not universal, equal, or natural.[36]

Throughout history, dating back to World War II, medical research was seen as a study to achieve results no matter at what cost the subjects experienced. The Nuremburg trials which involved suffering, non-consented humans, no scientific merit and ending sometimes in death were all conducted with no ethical principles for medical research.[37] These trials were conducted with no human remorse or conscience. The subjects were seen as only subjects and the goal was a scientific revelation. These cases also happened to indigenous populations without obtaining consent throughout the community.[38] Most of these research projects did not benefit the subjects going through the process, and they were neither consensual nor had guaranteed safety. The aspect of human rights was neither present nor consented.

The problem with human rights and vulnerable populations is that not all vulnerable populations think they have a right to disagree or own their human right. Most vulnerable people will agree to any research study because they do not understand enough of the process and do not know that they can ask questions, they only see benefit until the benefit is taken away too quickly. These people do not have the same access to healthcare as people in industrialized countries. They are deprived of the same knowledge and freedoms that advantaged non-indigenous counterparts have. This is due to the fact that the indigenous population may or may not have realized their human rights to self-determination, autonomy and self-government, freedom from discrimination, and freedom of choice.[39]

The principle of respect for human dignity holds an important place in intergovernmental dealings with biomedicine that have been approved since the end of the 1990's, such as the Universal Declaration on the Human Genome and Human Rights of UNESCO and the Convention on Human Rights and Biomedicine of the Council of Europe.[40] In clinical and research settings the respect for human rights is prominent. In order for a person to enter into an

agreement with a research project, that person should have their full human rights intact when understanding and accepting the legalities of the project. The declaration explains that all human beings are equal and deserve the respect of human dignity, human rights and fundamental freedoms.[41] Human beings are equal in the common values and moral principles, and therefore every human should be treated equally as well. Generally speaking, humans should be considered equals in terms of dignity, justice, rights, opportunities, freedom, benefits, and obligations.[42] These principles are to be respected across all populations of the world. There is no country or area of the world that should diminish the aspect of human rights.

II.b.iii. Universal Ethical Framework:

Bioethics can be used universally. This framework of ethics and morals takes the basis of bioethics and expands it beyond each individual's boarders. The universal ethical framework excludes religions, culture, and individual community concerns. This framework develops a connection between bioethics and people around the world. No person is considered different; instead, every person is a human being in which all moral and ethics are on equal ground around the world. This framework encompasses the previous stated ethics principles along with human morals of right and wrong. A global ethical framework includes the values human beings share with the basis of ethical principles.[43]

Bioethics discourse can no longer focus only on the industrialized countries, but need to also focus on the developing countries under the bioethical frameworks continuation to grow.[44] This framework spreads to all areas of the world including these developing countries. These countries may be underdeveloped, but they have the same political problems that most of the world goes through as well. Less developed countries should not however, have to be scrutinized and judged for their choices. Their cultural, traditional, and religious aspects may be

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different than those of the developed countries, but they should not be oppressed by the views of the power countries. The morals and values of all humankind should be universally respected. Many under developed countries, however, may go through different complications of medical research than in developed countries. Some communities such as Arab, or tribal communities, consider the male or chief as the head of the community; this in turn will have different considerations than individual responsibility. Involving medical research, the individual may not be able to use their autonomous right to be in the study or not. The autonomy of individuals is not honored over communities.[45] Autonomy and informed consent in these cases are not considered individually. The whole community is considered as a whole under one consent. This may be questionable to the outside observers, but this is the culture one needs to be aware of when entering a new community to conduct medical research. These populations still deserve their human right to autonomy, though their culture may have a diverse way of observing this right. This ethical framework may need to put more pressure on these underdeveloped populations in order for these main bioethics principles to really take place.

The universal ethical framework also tries to concentrate on three main areas that relate to the previous stated bioethics principles. These areas include: the drive to reduce health inequities; distributional justice; and the health of marginalized populations.[46] Health inequities are the unfair and detrimental consequences to communities that are connected to the laws that govern civilization.[47] These inequalities prosper throughout the world. Many are not considered a huge priority if not in an urban-like area. Social justice remedies who receives global goods in which statistics show the individual level and the level of wealth in order to see the equality.[48] This does not just occur in undeveloped countries; this can also occur in developed first world countries. Lastly, the marginalized populations are cause for concern due to the discrimination,

racism, and the continuous injustice of people.[49] This framework is the grounds of global bioethics. It allows for the challenges and demands of up and coming ethical issues throughout the world. This framework, tied in with basic ethic principles, is a basis for the development of global bioethics and a universal framework.

The basic ethic principles of autonomy, justice, and beneficence, combined with the areas of reducing health inequities, distributional justice, and the health of marginalized populations, allows a framework to work towards globalized bioethics. This combination of principles and themes will create action in underdeveloped countries, and present a need for developed countries to fight for a common ground when ethical issues arise in the medical field.

III. Minimum Harm Criterion for Research in Pediatric Medicine:

This Section will provide insight into parent and patient consent, risk versus benefit analysis, IRB guidelines and safeguards for approval of pediatric research, the difference between therapeutic and non-therapeutic research, standard of care versus drug research trial, and lastly defining minimum harm criterion.

III.A. Pediatric Research Ethics:

This chapter will explain the role of an Institutional Review Board, IRB, and the safeguards that they implement to conduct ethical research. These safeguards also need to coincide with ethical frameworks involving the individual researcher because once research is approved, there needs to be an ethics consultant guiding the research in the ethical direction when no eyes are watching. The need for ethics consultation services all pertain to informed consent from patient and family, along with the risk/benefit analysis. Quality ethics consultations can provide a higher quality of communication, unconventional quality of care

options, managing conflicts of interest, and addressing the concerns of the family and patient by relaying them to the clinical research team.

<u>III.a.i. Patient and Parent Consent:</u>

Informed consent consists of three components: consent must be informed, voluntary, and have competency.[50] The three areas of consent are taken for what they are worth and sometimes are only in the judgment of the medical professional.[51] Most research studies are based upon a theory of open consent which allows the subject to voluntarily consent to the medical research, but on the basis of the information given to them provided by the researchers.[52] Researchers give the patients enough information that is necessary for them to consent to the research. This is not necessarily a communicative dynamic. This process entails medical information that may not be understood by the recipient nor is the information given in a manner that is simplistic to the common man.[53]

Today's medical research agenda given during an informed consent process is esoteric and highly distorted for this culturally diverse society.   The medical community should take the time to care for their subjects and or patients to the extent that no confusion is brought on after the informed consent process takes place because of medical language used.[54] The informed consent process is and should be dedicated to the subject being: informed through common language with all questions pertaining to their own personal needs answered through persistent discussion; voluntary on behalf of the patient not being coerced by any form of cultural didactics or economic perils; and the subject must be competent in the way that their understanding of the medical information can be relayed back to the researcher with a proper risk benefit analysis.

There is no specific age that a child can legally consent other than when they reach the age of eighteen and that is considered a legal adult. Children are all completely different and

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have different levels of understanding. Most researchers see that at the age of fourteen or fifteen, children have enough knowledge and understanding to assent to medical decisions. Children either can be asked to make decisions, but they will be overwhelmed and not intellectually ready to make their own decision or children can make an intellectually developed choice, but never be afforded the right to make the decision because they were denied the opportunity to decide for themselves. There is this fine line that either inhibits authority of choice or denies that right.

In pediatric research, a researcher needs a parent's consent and a child's assent to conduct the trial based research.[55] The problem with consent and assent in medical research is the informed process of these decisions. Pediatric research is esoteric in the sense that the research may miss out on the vital understandings, usefulness, questions, and evaluations that are present during the informed consent / assent process.[56] Most research is done in adult medicine and based upon the conversations held with adults. However, the US guidelines also state the problem such that all children can only formally assent and at times the assent can be waived if direct benefit to the patient is only capable through medical research.[57] Even though the patient will be receiving direct benefit the risks and harms to the patient may be greater to the individual child then the direct benefit of being healthy, but because they are a pediatric patient they are not formally allowed to consent to pediatric research and their own assent is limited.

Article thirteen in federal law indicates that the rights of children include giving information and obtaining it in a way of understanding the information by media, oral communication or any other form that allows the child to choose.[58] However, this article is often ignored since most consent processes are centered around the parents of the child and not the child patient themselves. Most researchers act as though children are not present in the conversation and do not add any valid contribution to the consent process.[59] To find out what is

in the child's best interests, researchers and parents need to discuss the situation with the child. The child may also add valuable information about their thoughts of the research and how it will affect them. The problems with consent and assent are leaving the child that is involved in the research out of the conversation.

A child should be presumed to be competent, and able to reach a conclusion about themselves in medical research because it is harder to demonstrate competence rather than spotting incompetence in a patient.[60] Every human should be considered a competent person until proven otherwise. It is harder to deem someone competent rather than incompetent based on a series of competency exams. If a child is able to understand the risks and benefits of their choices then they should be allowed to participate within their own realm of healthcare. A child that is capable of their own point of views should have the right to express those towards their own care.[61] By explaining the research in a way that the child patient can participate in their own care, and strive for better communication between the research team and family, the quality of medical research consent / assent process will be strengthened.

Quality clinical ethics consultations would be able to tailor the informed consent process to fit the individualized family's needs for the best interests of the patient. The ethics consultation will provide a stronger quality framework in the initiation of medical research. Respecting each child's views and how they think will allow for a trusting relationship between the researcher and family in order to make a stronger initiation of medical research.[62]

III.a.ii. Risk vs. Benefit Analysis:

The problem is research must be tested, and eighty percent of all children's drug medications are not tested on children to either confirm safety nor efficacy of the dosage.[63] Children entering these drug trials are to be assessed by risks and benefits before entering the

research studies. This risk benefit assessment is by the researcher and either classified into three categories: minimal risk, minor increase over minimal risk, or more than a minor increase over minimal risk.[64] These three categories are based off of the researcher's interpretation of risk to the patient in the medical research. If the definition of risk-benefit analysis was broken down, risk would be interpreted as a vague word to cover all the possible harms and costs of the research and the benefit would include all the direct benefits to the patient involved in the study which is a very loaded and a vague term.[65]

If research isn't done on children specified in a controlled research trial then every child remains an experiment in everyday life.[66] These drugs are being tested on children in a controlled environment, but there lacks proper communication of the risk benefit analysis that pertains to each individual child patient. Risk benefit analysis is often misunderstood and misinterpreted because if the benefits outweigh the risks then the research should be allotted.[67] Weighing the risks and benefits of research for an individual is complicated, and should be a thought out process that is individualized per patient. Many researchers also focus on the possibility of direct benefit to the child patient.[68] This direct benefit may be overly focused on when it is just a possibility and not a fact. The research in children is necessary to improve medication standards, but if the researcher does not properly explain in a language that is understood by parents and child subject, then the risks and benefits have not been properly relayed to carry on with the study.

Helenski reports that the researchers are to first focus on the concerns of the individual's risk rather than the collective benefit.[69] This entails that researchers need to further communicate effectively with the child patient and parents that the research they are involved in is a possible benefit for future patients rather than the patient currently enrolled in the trial. This

way, parents and children will be able to weigh their own risk and benefit analysis before entering into a trial. These risk benefit assessments need to be tailored to the individual child patient rather than to a child population.

Researchers need to explain the risks of the research and listen to the child in order to understand their views and what worries them most because some particular harm to the child might not have been a concern prior to the researcher consulting the child patient.[70] Each individual patient may think that one risk is greater than another depending on their own deep rooted values. Harm is a misunderstood word in research because it is complicated and possibly invisible to the naked eye because there are so many differing viewpoints.[71] These harms or risks could be something as simple as going to bed five minutes later than a normal bedtime, but a child may find that inconvenient or uncomfortable because it is upsetting their normal everyday sleep schedule. Listening to the needs of the child patient and understanding their worries will reduce harm and ensure protection of the patient.[72]

The physician must pose a level of understanding and develop a patient relationship in order for their patient to feel at ease when talking about their future endeavors in treatment. This is seen through a physicians' bedside manners. The dialogue with the patient, respect and understanding of their concerns are important in order to understand what the patient is going through. Stepping into their shoes, so to speak, allows the physician to relate and make more quality decision of care.

In the past, the moral foundations of research were based upon the trust and medical beneficence of the physician and their subject or patient.[73] Research should have this trusting beneficent relationship between physician and patient. However, with this trust model came researcher paternalism which influenced the information given to the patient based upon risk-

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benefit assessment and did not include social value.[74] A patient's social values stem from their cultural backgrounds, values, wishes, and wants out of their own life. These aspects of the subject in research should be taken into consideration to provide a quality of research that does not only consider physical or mental harm, but will not harm the patient's social aspects of life as well.

Today's research is more than a risk benefit analysis when each individual's quality of life varies in differing degrees. Research is still susceptible to coercion, manipulation, inducement, misconception, and exploitation, however, awareness of varying approaches to informed consent in medical research that fits varying individuals of diverse backgrounds requires a quality research ethic to which all patients deserve.[75] Clinical ethics consultations would be able to provide researchers with the proper skills and knowledge to assess the situation with their child subject and be able to properly adhere to the standards of medical ethics in research. This way, clinical ethicists have a working hand in the on-going process of medical research with pediatric patients.

III.a.iii. IRB Guidelines and Safeguards for Approval of Pediatric Research:

Institutional Review Boards, IRBs, have historical ethical standards that need to be embedded into the framework of approval. These standards have allowed IRBs to recognize adequacy of the study, minimization of risk, risk-benefit ratio, protection of confidentiality, promotion of informed decision making by subject, potential conflicts of interest, and equitable section of subjects.[76] These codes, declarations, and reports now have become iconic ethical standards for reviews of medical research with human research subjects.

The Nuremburg Code was a set of ten points that included: voluntary consent is essential; all suffering of mental or physical capacity should be avoided; there should be minimal risk to

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the research if any at all; and all human participants have the right to withdrawal at any point in the research study.[77] These ethical criteria set out a foundation for medical research that has provided a model to which all research professionals should abide by in terms of research participation using human subjects. This criteria, however is vague and was further developed through the Declaration of Helsinki which conquered the aims of medical research per physician and subject interests. The Declaration of Helsinki states: each subject should be well informed of the aims, methods, and sources of funding if possible conflicts of interest arise in their medical research study; international association of the researcher; and possibilities of the risks and benefits the subject may entail.[78] These two codes were derived to be applicable in all research in a way that it safeguards the subject from exploitation, forced research, suffering, harm, and respect for human persons.

The Belmont Report was addressed in 1979, in order to address the ethical conduct of research into four principles of ethics: justice, beneficence, non-maleficence, and autonomy.[79] These four principles are applicable in every culture, and religious atmosphere around the globe. These principles allow a person to have justice, and autonomy during research and on the other side of the research the researcher is beneficent to their subject and non-maleficent. UNESCO, in 2005, developed the Universal Declaration on Bioethics and Human Rights which then attacks the ethical issues pertaining to human rights, respect of human subjects, and recognition of freedoms in scientific research.[80] The historical knowledge of medical research allows IRBs to reflect upon the ethical implications of erred research and therefore, fix present day medical research for human subjects entering this realm of healthcare.

Research should go through a gatekeeper such as an IRB or ethics committee in order to provide independent protection for human subjects in medical research.[81] Many suggestions to

regulate the IRB forum or ethics committee has been designed, but not nationally standardized.

These professional associations should have access to updated ethic codes, national ethics

forums to hold debates on ethical problems and aid in the progression to standardize solutions.[82]

National standards need to be set in order to produce a higher standard of quality in pediatric

research in order to have effective ethical interventions. Along with these national standards,

journals should not publish articles without the approval of an IRB along with these new adapted

standardized requirements.[83] If pediatric research approval can be seen as a consistent

requirement then the quality of research produced will become a more ethical stature.

Ethical review boards have become a standard regulatory requirement in the field of

medical research that are now designated an IRB. These IRBs are a structured system of board

members that regulate the ethical responsibility of medical research practices of human

participants.[84] These IRBs are federal, private, independent, academic, and military based which

spans across many realms of medical research. These institutions are set out to defend research

participants, approve ethical research studies, and be the gatekeeper to present day culturally

competent ethical research. If an IRB is federally funded or the institution conducting research

has federal funds, then the federal Common Rule is enacted to which the IRB balances the risks

of harm and potential benefits.[85] These requirements are regulated when any institution receives

federal funding, but all IRB's weigh risk benefit assessments regardless. There are two types of

possible benefits of medical research that the Common Rule can assess: benefits to participants

or the knowledge that results in the research under the ethical restrictions.[86]

The Food and Drug Administration, FDA, also has regulatory requirements during all

steps of their research studies including: the risks of all research subjects are minimalized; the

risks are reasonable to the benefits received; and the informed consent will be sought after from

the subject or authorized representative.[87] These requirements are set forth by the FDA with all prescription drug use, commercialized drugs, or placebo-controlled trials to which research participants are in a trial to study the drug effect on participants for the community or to establish a prospective research study. The U.S. regulations, codified at 45CFR 46.102, states what medical research is, but does not demonstrate particular or specific clarification which the Belmont Report, Helenski, and Nuremburg regulations try to adhere too.[88]

Along with the IRB or ethics committees, the researcher should also have experience in pediatric research in order to conduct a proper ethical trial. The training involved should be a requirement involving effective communication with children, and power dynamics.[89] The research can only be successful if the researcher possesses these skills allowing the child subject to feel their well-being is cared for and that they are important to the researcher.[90]

Along with subjective attitudes and ways to conduct research, the researcher should also abide by the codes of ethics which the IRB would also require during their approval of the trial. Researchers are advised to: respect the rights of the subjects, manage conflicts of interest, follow practices for safety, conduct responsible research, and conform to policies abided by the institutions they work for.[91] The researcher is as responsible and is accountable to the approval of the research study as the IRB or ethics committee. However, each researcher and institution should uphold their oath to ethical research to the best of their knowledge and strive for higher quality research by implementing a clinical ethicist to further education programs, checklists, and proper conduct of the codes of ethics to continually improve the process.

III.B. Minimum Harm Criterion:

Therapeutic research is the research conducted that brings a direct benefit to the child patient involved in the research trial. Non-therapeutic research is the research conducted that

may bring a direct benefit to the child, but it is not a foreseen event, instead the intended effect of the trial is to have knowledge gained for future patients. The two differing trials will bring about conflicts of interests that a clinical ethics consultation would be able to diffuse. This section will discuss the implications of not addressing the difference between standard of care and drug research trials. Clinical standard of care and research trials are two separate entities that need to be understood as two separate actions of care. Minimum harm also needs to be addressed in pediatric trials because harm can be unnoticed to adults, but may actually be a concern for children. Ethics consultations would be able to communicate these concerns and better address these issues with the clinical team.

III.b.i. The Difference Between Therapeutic and Non-Therapeutic Research:

Clinical medicine is sought to be protecting the patient's wishes and well-being while enduring clinical care by healthcare professionals.[92] Clinical medicine is ultimately the healing of the patient with their best interests at the forefront of decisions. Physicians and healthcare providers act beneficently, and non-maleficently in order to provide the best quality of life to their patients. Research medicine is chosen not solely on the basis of the patient's wants and wishes, but on the success of the research study.[93] Yes, research is not based off of the patients and or subjects values of receiving quality care medicine. However, research should be combined in a tactful way that it fuses clinical aspects of respectful care, and helpful communication to which the trials one is embarking on is a trial and not a cure. This can be confusing to patients and parents at the initiation of the research study.

Therapeutic research is often at times confused with treatment, but usually poses as a research that has fewer problems than non-therapeutic research.[94] Therapeutic research proposes a more positive outcome and may have better results either for the current patient or for future

patients. Therapeutic interpersonal interactions are based upon the emotional comfort from medical staff, controlling the security of the patient.[95] These detections of therapeutic research can have many ranges and can be individualized per the child patient involved in the research study.

Non-therapeutic research usually has little to no benefit, but the risks are greatly reduced. Research is not meant to be divided into therapeutic and non-therapeutic because then the research is divided into two strict categories which may not benefit each child patient or may benefit the group as a whole.[96] Each individual sees their acceptance into research as one or the other. After all, potential benefits of research are reasons to which patient's agree to the research in the first place.[97]

In many cases, most research participants and family members do not understand the extent to the research study and presume that the general knowledge obtained during the information process may in fact exclude the therapeutic goals of the individual participant.[98] The first steps in misconstruing the facts of a research study is a misconception about what the research study will actually do for the child patient. Sometimes, a researcher needs to understand and develop a relationship so they know the patient in order to directly focus the goals of the research more successfully.[99] This way family members and the child patient will understand the research goals instead of their intended hopes, which in other terms is the therapeutic misconception.

There is a therapeutic misconception that many enrollees envision their research will be. This misconception is that the research study an individual electively chooses to be a part of does not necessarily have a curative benefit to the individualized underlying prognosis.[100] This means that a subject may choose medical research because it is their last option of curing the disease.

However, medical research is usually trial basis and not considered curing patients. Clinical research focuses on the research which may or may not benefit the patient, but is certainly not a cure. This therapeutic misconception can be dissuaded through proper communication and open dialogues throughout the consent process.

Research however, can learn from clinical practice in the sense of being compassionate, caring, and honest during the process of human beings last hope in the sense of care. Researcher's concerns are based upon the outcomes of their research, but should also be simultaneously regarding the welfare of their patients and trying to respect their last quality of life with as much care as possible.[101] The ethical duty researchers have to their subjects still lies with autonomy, justice, beneficence, and non-maleficence that should be a guide in ethical practice to uphold the compassionate side of clinical practice and be able to see those values extended into medical research. Clinical ethicists would be able to act as positive enforcements of ethical practice for researchers and their subjects.

III.b.ii. Standard of Care vs. Drug Research Trial:

The standard of care in medical practice is to treat patients until they don't want to be treated, have their best interests at heart, and do what is necessary to keep them alive. In medical research, there is no standard of care because medical research is not a treatment. Many individuals are confused by this concept. It may be seen as the therapeutic misconception that parents see the primary goal to research is to advance the individual patient's best interest.[102] Instead, research is to gain knowledge for future benefit, and there may be some direct benefit involved. However, parents may see as their understanding of medical research as another treatment option for their child.

Most parents also see research as a final hope for their child's health. Researchers must explain that the research may not always result in a direct benefit to the child.[103] If this explanation is not explained properly then the child will have hope in the research and so will the parents. Most research is for future benefit and the individuals involved are not receiving direct benefit. Without proper communication, parents and children will be misled and in the end be indirectly harmed in the process. Present systems do not protect from harmful or useless research, but there should be new attention placed in this area.[104] Most of these "harms" are not physical, but psychological or only harmful to the individual patient.

The language barriers are the first complication in the initiation of ethical research.[105] An ethical understanding of research in a multi-linguistic society should have multiple options for accepting the research process in the informant's native tongue. The language barrier may consist of using medical terminology the common man would not be able to understand. This also causes conflict between the perceived informed consent and the patient who decides to just go along with everything expecting a therapeutic benefit. The use of informal language and precise forms of communication should be applicable when discussing the research with human subjects.[106] These ethical systems also vary between religions and ethnicities in research.[107] There may be coercion involved in culturally diverse communities that stem from the subject and their families. Many families and subjects that are in a less developed country, have a language barrier, have a lower economic status, and think they will be incentivized for the research that the family member allows themselves to be involved.

In one study, a physician explained two of three concepts involved in the research, but the parent did not understand a single one of them.[108] In most cases the communication barrier resists the essential knowledge needed to understand that the trial participation is not a treatment

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option. It also does not allow for the parent to understand the reason for the research let alone to understand the reason for no more treatment options. The easier the communication is, then the easier it is for a physician to refer a patient to a research trial.[109] However, new strategies of explaining research versus standard of care options need to become more effective to provide honest discussions about the continued course of action and address the concerns that may arise.[110]

There should be an established respectful partnership between the community and the researchers.[111] This way the researcher can be involved with the cultural aspects of the community to which they can obey by the cultures rules when conducting research. Secondly, they can create a common ground of respect and open dialogue which can bridge the gap in miscommunication and misconceptions of the research conducted. Lastly, ethical guidelines in conducting research in other communities or multi-cultural societies will guide the research in ethical manners, and at the same time researchers can become more culturally competent conducting research in other diverse cultural communities.

The clinical ethics consultation would provide an additional support to determine the capacity to which a parent understands the research material for their child, and to discuss the appropriate decision regarding the "non-treatment" endeavor in care.[112] This consultation will serve as a stronger communication safeguard to strengthen the understanding of research material and therapeutic misconception. This then allows researchers, parents, and children to feel comfortable in their decisions in pediatric research.

III.b.iii. Minimum Harm Criterion:

Risk should be minimized to the greatest extent possible within the constraints of sound medical research.[113] Harms do not only include physical injuries by also distress, psychological

harm, social, economic, or legal.[114] Many of these harms are not thought of unless they are

physical, but all researchers should be aware of other possible harms when conducting ethical

research. Risk or said harm in medical research should not be greater than minimal to any

human being. Minimal risk is defined as the risk that is not greater than everyday life risk that

one may experience as a child, including routine testing, psychological exams or physical

exams.[115] This makes for minimal risk to a healthy child an extremely small category in medical

research.

The everyday risk standard is understood to be the probability of harm comparable to all

the risks an ordinary person would encounter thereby setting a standard for all persons.[116] This is

a very vague statement to suggest that every human being, every day is in the same setting, the

same atmosphere, and the same lifestyle. Attempting to combine risk from children's overall

activity, a study has shown that one in two hundred and fifty children risk injury per day, and

that four in a million children are at risk of death per day.[117] This is the probability of most

children, but not all children.

The concept of minimal risk extends to the rational that the research does not impose

more than minimal risk to the child's typical everyday life.[118] This means that the researcher

also needs to investigate what constitutes each child's typical everyday lifestyle in order to assess

whether they are a candidate for the research study. Risk is measured in degrees and the degree

of risk that is acceptable to the child patient will depend on the importance of the study, the

potential harm, and the direct benefits to the patient.[119] Promoting better quality information

which can in turn improve research standards will provide a higher quality of care for child

patients and promote higher ethical quality in pediatric research trials.

It is the responsibility of the researcher to provide age appropriate information to the child involved in the research study.[120] The researcher may need to discuss the research in a more relaxed language in order to articulate the common medical knowledge in relation to a child's terminology and understanding. Defining risk to a child patient with their perspective in mind and not from the orientation of the adults should be a practical standard.[121] Along with the understanding of the research risks and benefits the researcher must also understand the child's normal everyday life.

The degree of risk needs to be researched in a way that both the magnitude of the event and the likelihood of the event need to be considered before beginning research trials.[122] This constitutes that a child may choose to be a research subject because the harm to their person is minimal and the rate to which it can occur is minimal, but any harm above these mentioned risks may not be approved by the child patient. This entails that every researcher needs to be aware at the reoccurrence of harm in a study, and the magnitude of harm. Routine examinations of the level of minimal risk in a trial will allow for comparison between a healthy child's harms and the patient involved in the study.[123] This can give a clear conception of the research and whether it is proceeding as minimal risk research.

Ideally, a child wishes no pain, no risk, and no inconvenience.[124] In medical research, this may not always be possible or easy to achieve. Researchers are able to manage risk that may require judgment or interpretation of their patient's wellbeing along with providing a framework for action rather than perspective protocols.[125] Change can only occur if researchers are capable of taking action for their patients if the ethical framework is stated in a way that the patient's best interest is a standard instead of the end goal being to promote knowledgeable research for future patients. Most ethical frameworks in medical research today need to be interpreted by

committees or boards who will most often make decisions by a case by case basis.[126] Ethics consultants would be able to ensure proper ethical framework in the field, and not just on paper. Protocols, and policies only go so far, but actions speak louder than words and consultants would be able to pursue a stronger ethical framework by being present alongside the researcher in pediatric medical research.

VI. Conclusion:

The cultural and traditional aspects are highly important to uphold when entering subjects into a research study. Benefits should always outweigh the harms. Full, autonomous consent should be a priority for the subject to make an informed decision. If there is treatment available, the treatment should always be offered. Learning from past research studies, we need to continually create and issue new ethical guidelines in order to protect indigenous populations and continually improve the ethical issues of medical research. The problems in medical research can teach future generations how to ensure ethical standards before, during and after treatment in trials. It is imperative that responsible documentation be consistently developed and made available worldwide to current and for future medical and research personnel, so that new ethical guidelines can cooperatively evolve when necessary and appropriate. First and foremost, respect for research trial participants, their lives and their culture must be priorities. The United Nations and its component Nations need to develop universal guidelines for ethical research to benefit vulnerable populations globally.

There is a need for quality ethics consultations in pediatric research. This need has been examined through therapeutic and non-therapeutic research trials, IRBs, differences in treatment and research, and lastly informed consent and the risk/benefit analysis. Clinical ethics consultants in a therapeutic or non-therapeutic research trial will be able to further explain the

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difference of the trial to the child subject and or parents. They will also be able to help the researcher with any ethical dilemmas in the initiation of the research trial. IRBs hold limitations in today's research with children, but ethics consultants would be able to carry those ethical requirements and standards throughout the research practice. These standards then will ensure a stronger more developed informed consent process that adheres to a specified risk benefit analysis per child patient involved in the medical research study.

These areas of research need to be solidified for the quality of ethical research to withstand patient scrutiny in today's society. There needs to be ethical, competent, and quality standards implemented within the research system. Clinical ethics consultations would be able to provide research staff with the proper ethical education to further quality research. They would also be able to guide researchers through ethical dilemmas and conflicts of interests in the initiation of research and throughout the subject's research trial. These consultants are there for the well-being of the patient child subject even though they may not directly benefit from the research trial they are still a priority in the absence of clinical treatment. Ethics consultants then can combine the aspects of compassionate care, effective listening, coordination of care, and conflict management to impose these standards in the pediatric research setting attaining better quality of care from the beginning to the end with the focus on the child patient's outlook of research.

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Chapter 7: Educational Features for Ethics Consultation in Pediatric Medicine:

Clinical ethics education is necessary in all of healthcare, but is especially needed in the pediatric realm due to uncertainty in real life medical situations. Clinical ethics is taught mainly through the adult realm of healthcare which performs on the principles of autonomy and justice. The basis of adult decisions is from a compilation of their own personal values and or personal characteristics that portray their meaning of quality of life. However, in pediatric medicine, ethics is not truly connected through personal autonomy and justice, but rather surrogate decision making by parental expectations of care and physician paternalism. Without the proper education of clinical ethics in pediatrics, medical standards will fall short of ethical pragmatism and medical self-worth. Clinical ethicists would be able to uphold furthering education, and exceed care expectations in pediatric medicine.

To ensure ethics education in the field of healthcare there is a four step process. First, physicians need to be well educated in medical school and also in their residency programs. The lack of ethics curriculum integrated into medical school and residency programs is unacceptable for quality healthcare. Second, this requirement should also coincide with nursing programs and management programs. Each of these professions needs a higher level of ethics education to provide higher quality of care for their patients. Third, ethics education should be implemented into the specialty areas such as in the clinical and research settings. This way all people involved in either of these medical settings are properly trained in ethics and educated to identify ethical conflicts or issues that may arise with those in their care. Fourth, and lastly, to ensure ethics education in healthcare is to implement the ethics consultation service thereby

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continually educating healthcare staff on ethics, and reinforcing the importance of this kind of care which will ultimately change the face of healthcare. Ethics consultation services will provide a higher quality care that will exceed the care expectations of patients, educate staff on ethical issues, diffuse ethical conflict, and promote quality throughout the healthcare organization.

II. Ensuring Ethics Education in Physicians:

Ethics education is lacking in physicians graduating from medical schools and extends into their residency programs. This education is necessary to be a physician because without ethics, physicians become more and more desensitized to their patient's care, and become more concerned by only medical necessities rather than a patient's overall well-being. Care in today's medical field means far more than diagnosing the medical illness and discharging a patient. Now, medical care involves quality of life, beneficence, listening, patient values, and patient goals or wishes. This care is a team effort, and it first starts by educating the physician in medical school and followed by reinforced training alongside their residency programs.

II.A. Medical Schools:

The Joint Commission of Accreditation of Healthcare Organizations has mandated that all hospitals across the United States have a system that is able to address ethical issues or conflicts in patient care. [1] This ensures that all hospitals have some type of service that is educated on how to deal with ethical conflict in medicine. However, most medical staff members are not equipped with this education nor know of clinical ethicists or ethics teams in their healthcare system that can help support the conflict at hand. Medical ethics curriculum needs to be developed through the structure of medical

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education in medical schools and residency programs. There is a hidden curriculum of values, and moral righteousness in medicine, however, there ceases to be a controlled perspective of structured principles, terminology, and goals of medical ethics in the present day curriculum which is lacking in acculturation and ethic fundamentals needed to practice medicine.[2]

Medical schools are the initial fight or flight paradox where either physician's will embrace their medical education or fail to uphold the foundations of medicine. Now their educational studies on ethics is becoming the foundation in their medical curriculum. Physicians should already possess virtues such as compassion, honesty, respect, and morality however, ethics education will take those virtues and develop physicians who can recognize ethical dilemmas and produce ethical solutions.[3] People become doctors because they want to care for someone or help people in need, but we do not educate physicians on how to diagnose an ethical conflict when one does arise. Medical schools need to provide enough education to equip "to be" physicians with enough ethics knowledge to not only diagnose disease, but also value conflicts, ethical dilemmas, or moral distress issues. Medical students are extremely bright despite their grueling class schedules, but without ethics education, the system fails to make them better doctors.[4]

Ethics is now a central place amongst the many specialty teams involved in decision making during patient care.[5] This should now be essential to medical school curriculum. Medical institutions vary in the education required in ethics which can range from four hours to one hundred and eighty hours of ethics education over a four year period.[6] Requiring ethics is not enough, there needs to be a universal protocol that initiates the necessary ethics education to actively engage in ethical conflicts within the

real world of medicine. There should be rigorous examinations on ethical theory and reasoning, clinical papers requiring integral ethics teachings and medical standing, case study analysis or conferences, hands on inpatient ethics consultation studies or approaches, and intensive practical courses.[7]

These classes should be taught in smaller group settings to develop ethical case reasoning, hands on experiences, and greater gains in moral reasoning rather than in a strict formal lecture format.[8] Professors have a vital role in creating ethics education. They are the ones who will show the importance of ethics within the realm of medicine. By sharing ethical dilemmas, problems, and conflicts and the importance of making sound ethical decisions to resolve the issue at hand will bind the culture of medicine and the ethical curriculum together to create a clear message of integrated quality ethics in healthcare.[9]

The success of the ethics education in medical schools will be based upon the collaboration of the faculty, administrators, department and students enthusiasm to create, uphold, and develop a quality program that adds to the already established curriculum.[10] It is not enough that ethics is important, but the new structure of the curriculum and university needs to be established before ethics can become universally required and prosper as its own. Along with structure, ethics should be considered to be a program that is developed throughout the four years of medical school so that the development of forthcoming physicians is sought to be: increased moral reasoning skills, ability to recognize moral issues, and establish ethical perspective during patient care.[11]

Medicine calls for more virtue based learning and a commitment from physicians that drives a new distinction of good intentions and ethics.[12] The physicians today are

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leaving medical school have embedded mixed messages of patient care and how the physician and patient roles are supposedly seen as separate rather than interrelated care. The ability to create virtuous physicians who can identify, analyze, and resolve ethical dilemmas and integrate ideals, customs, norms, and institutional or hospital environments into their medical diagnosis is the ideal for the new age physician, and only formal ethics training can oversee this advancement for higher quality care.[13]

II.B. Residency Programs:

Up until the early 1980s many residency program directors did not see that teaching medical ethics during residency was neither productive nor necessary, however, in 1984, the Association of American Medical Colleges published a report stating that a physician is required to meet a high standard of humanistic behavior which would be taught in the necessary classes of medical ethics.[14] That being said, medical ethics teaching in residency programs is fairly new, and still being carefully navigated during clinical rotations. Jacobson has done a study that showed that about seventy four percent of residents want more ethics training in specified areas of medicine.[15] It is now becoming a need and not a subtle change in medical care. It is now important to teach clinical ethics beyond the classroom and it is not enough to just be seen in medical school, but in the residency training programs where physicians can reinforce and apply their ethics knowledge to practical experiences.[16]

Ethics programs within residency should focus on: voicing disagreements appropriately, ethically participating in team medical care, weighing patient rights, maintaining ethical and moral being in a complex situation, and resolving ethical conflict in a diverse cultural world of medicine.[17] If ethics programs focus on certain acute issues

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pertaining to their everyday work, then they are more able to absorb the ethical problem before it occurs. This way, physicians can consistently recommend ethical solutions to reoccurring problems or change the culture of the environment so that the problems occurring do not happen again. A preventative ethics approach is more sustainable in the clinical realm than a reactive approach. Reinforcement of ethical skills from preclinical education helps develop future physicians who impact their patient's lives not only with their medical skill, but with positive attitudes encouraging the ethical commitment to quality patient care.[18]

Sometimes in clinical residency programs, new physicians are only taught about the medical knowledge of the clinical case, and not about the patient as a whole. This is where residency programs need to address not only the resident, but also the attending or other older residents about medical ethics. Education at this point comes from the top down. Residents see the culture of the organization and their attending physician as people that lead the field of medicine. The best of the best. The residents will follow the actions of their attending physician and what is the "norm" at the facility in ways of caring for the patient. If a senior staff physician is unable to provide key aspects of directed medical care through training and essential developmental skills then residents will inescapably pick up bad habits of medical care.[19]

The surge of medical ethics upbringing in residency programs was for the desire of more compassionate and less dehumanized physicians that can care for their patient even if constrained by technological advances and new ethical dilemmas.[20] The mastery of skills a physician will need to be competent enough to unravel ethical dilemmas are derived from medical school and developed in residency. The values most frequently

recommended or taught are accountability and compassion.[21] Most residents favored

learning these values through practical experiences in the inpatient or outpatient clinical

setting. [22]The American Board of Internal Medicine has begun to evaluate residents on

their interpersonal and communication skills as one of the prerequisites for board

certification.[23] These values and moral intentions of young physicians would benefit

patients more than ever if it were tested during and after medical school and residency.

Ethics competency can thoughtfully engage patient values, and communicate

compassionate care. The goal of educating ethics to residents is to make them better

physicians who can attain a higher quality of care for their patients. To do so, these

physicians should have competency in: 1) recognizing the ethical issues as they arise in

the clinical setting, 2) analyze the ethical dilemma at hand and give concise ethically

justifiable courses of action, 3) communication and other practical skills that effectively

implement the course of action, and 4) to be able to judge the situation at hand to ask for

other ethical expertise if necessary.[24] With the basic understanding of ethics in residency

programs and hopefully the furthering of ethics education from medical school

curriculum, residents should have the ethical dimensions to assess the situation at hand,

communicate sensitively with the patients and other clinical team members, and propose

succinct medical treatment plans to further provide a higher quality of care to their

patient.[25]

III. Ensuring Ethics Education in Nursing:

Ethics education for nursing programs is essential to quality patient care. Nurses run

hospital units, and are closer to their patients than any other specialty care. Initial nursing

programs, whether it be an associates or a bachelor's degree, does not involve ethics

education enough in their practice. The nursing management programs or development of nursing management through years of practice may not always prepare nurse managers for ethics conflict, moral reasoning skills, ethics rational, or for effective conflict resolutions. Therefore, nurses need ethics education in their nursing programs and management programs to effectively promote patient care and efficient staff to drive overall quality in their care.

III.A. Nursing Programs:

Everyone begins as a novice. No one is an expert initially. Knowledge is imparted on nursing students through skilled environments, clinical teaching, trial and error, theoretical knowledge, and theoretical and prior knowledge gained through education.[26] Without proper education a nurse will experience moral distress, distrust in the healthcare system, sensitivity to personal challenges, and lack of knowledge to problem solve. Education is far more than learning concepts and skills. It is the application of education that is so crucial. Patients see good nursing care as the caregiving that addresses the need of the whole person and not just the sickness.[27]

The ethics education of nursing should promote moral reasoning skills, ethical knowledge, ethical principles, codes of ethics, moral sensitivity, and conflict management.[28] With this education, nurses will be able to identify the ethical issue and be able to properly address the situation or call upon an ethics consultant to help with the conflict at hand. The problem is not always identifying the issue. The problem lies with addressing the issue at hand. Most nurses are able to identify the right thing to do, but it is the assertion of presenting the issue at hand to the physician or other staff members and to cope with their own moral distress about the conflicting situation.[29]

The power structure of the healthcare organization plays a vital role in whether nurses feel comfortable enough to voice their moral conscience for their patient's care or to ignore their own opinions which may violate patient rights or respect of patient choices.[30] Students in nursing schools are young, inexperienced, and sensitive to their patient's needs. They are not desensitized to the well-known fast paced world of medicine quite yet. They have the time to listen, react, and question patient care. If they are being taught to accept the current standards of practice in medicine by unequivocally not voicing their grounded opinions then educators and experienced medical staff are ignoring the ethics of patient care. Students should be able to develop their voices to defend their positions rather than being told they are wrong or intimidated into feeling they are not allowed to express the wishes of their patient.[31] They should instead be taking ethical action to advocate for their patient and seek ways to promote patient wishes and goals not hinder them.[32]

Within the classroom, nurse education curriculum should include teaching ethics and a strong emphasis on the identification, analysis, and appropriate actions taken in order to address the personal or professional problems dealing with patient care.[33] A nurse should abide by the codes of ethics, patient principles, and professionalism. Their own personal moral values may however, conflict with the patient's own moral values or wishes. This situation can also cause moral distress for the nurse on how to properly respect their patient's wishes without feeling morally distressed about the situation at hand. The student should learn how to cope with a conflicting values situation in order to respect the patient's autonomy, ensure trust, and identify the conflicting feeling so they can better serve the patient's needs and act on the patient's needs rather than one's own.[34]

Separating one's own personal values from the reaction of the conflict at hand is a difficult situation. The concepts learned from ethics education will help incorporate the ethics principles, and theology learned in order to communicate effectively towards the patient's needs based upon the standards practice of care, codes of ethics, and provide a professional course of action.[35] Ethics education will promote a higher quality of care through the knowledge gained by nursing students who have yet to be directed by desensitized patient care. It will also provide an elevation of moral stress on the floor and the culture of the unit. This education can provide the technique and skill to resolve most patient issues, and in the end the patient will have not only been cared for medically, but will have their entire being well protected and fought for. Overall, nursing students should exemplify human dignity, portray professional values, respect autonomy, ensure trust, and initiate conversation in moral conflict situations to achieve the best of patient quality care.[36]

III.B. Nursing Management:

Managers in general should uphold the organization's values and develop, influence, and teach these ethical standards to their employees so that these concepts flourish throughout the culture as a whole.[37] Nursing managers should develop their staff throughout their career rather than teaching them one time upon orientation and never furthering their education; this will actually hinder the organization's prescribed culture and create unwanted norms. These diverging feelings and non-developed culture creates a climate of moral distress and unethical complexity that has potential to cause harm to either the patients, staff, and ultimately causing conflicting cultural values that execute poor staff ratios and high turnover.[38]

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If nurse managers used effective and efficient education that problem solved to make nursing more competent in identifying the ethical concern in a patient situation then not only are the educational standards set at a higher level, but also encourage problem solving and conflict management skills that reflect competent nursing staff.[39] The competency of nursing staff does not only fall to the individual's drive to understand and learn within their organization, but it also falls on the management staff to uphold and educate them along the way. Education does not end in the classroom setting, nurses need real clinical experiences and real clinical cases to better understand the ethical dilemmas and scenarios that they too may face in their hospital unit. It is better to be able to identify the situation before it becomes a dilemma. Moral dilemmas arise when values are at conflict with one another whether it is the organization, staff members, the patient, or the family and there lacks consistency between the conflicted groups.[40]

The best interests of the patient is the best course of action that should be taken, but may also cause stress, anger, depression, frustration or feelings of worthlessness for the staff because the preferred course of action may conflict with organizational values or personal morals.[41] Quality of life refers to the degree of satisfaction that people experience life as a whole pertaining to physical and mental health and well-being.[42] Everyone's beliefs are different and should be respected in the sense that the patient's best interests are at the heart of the medical conundrum. The best interests standard demands the focus on the patient's current needs and response to social mores, values, and situational stability.[43] Promoting the patient's legitimate interests uses the principle of beneficence, meaning doing well by the patient, and raising the relationship between medical staff and patient to a more interconnected level.[44]

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Within the organization the nursing management staff members should work towards encouraging their staff to become more educated in ethical conflicts alongside working towards meeting the environmental culture that exudes a meaningful work ethic to strive for higher quality and care. This power from the top down approach requires management to foster participation in patient-staff decision making, develop trusting relationships between patients and co-existing staff members, respect for one another, and accepting free thinking adding to goal accomplishments of the hospital unit or organizational whole.[45]

Nurse managers should have the same or similar morals with the organization they are working for so that they can support their staff in ethical conflicts and provide solutions to the problems that arise based upon their own moral convictions and the organizations.[46] Mangers should be a guide to new employees to extend their knowledge and values of the organization to new comers and show them how to resolve situations in the future. Nurse managers are there to teach oncoming employees to be masters of their own skill set. Internal values of patients of staff members or values of the institution drive quality care and when those values are in conflict the best course of action is to minimize harm, act in the patient's best interests, and devise a conducive plan to resolve the disagreement at hand.[47]

Nurse managers are also there to mold and complete ongoing education for staff members that have already adapted a skill set to solve ethical contradictions, but still have more to succeed in to be competent in ethics discourse. There is always learning to be done, but it is one of the main jobs of the nurse managers to constantly teach their fellow employees throughout their nursing careers. It is their duty to act in the best

interests of their patient, alongside their staff members. With proper education in ethics, patients and staff members will provide a higher quality of care. Creating good quality care is and can be an ethical dilemma that can be averted with competence and on-going education in ethics.[48]

IV. Ensuring Ethics Education in the Healthcare Setting:

Ensuring ethics education in the healthcare setting pertains to clinical medicine and research based medicine. In the clinical setting, ethics education is important based upon the ethical conflicts that could arise during patient care. It is important to know some basis of clinical ethics so that if an ethical conflict arises, one can acknowledge it and resolve the situation at hand based upon the patients best interests. In the research setting, ethics education is important because research patients may be involved with unethical research, or misguided information. Again, it is important to identify the situation and resolve the ethical conflict. Ethics education will provide a higher quality of care in the clinical and research settings of medicine.

IV.A. Clinical Setting:

In the last 20 years, medical ethics has become a key component in medical training.[49] Ethics education is becoming a standard curriculum amongst medical providers. Without an effective curriculum, physicians will not be able to acknowledge ethical conflict or be able to implement effective solutions to problems that arise in the clinical care of their patient.[50] If ethics is implemented at an early stage for education, then the positive outcome of having competent professionals in ethics when dealing with patients who need a higher quality of care in the intensive care units for example will reduce the time spent during end of life care decisions.[51]

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Physicians take an oath to medicine and ethics in order to provide their patients with the best care that benefits them and their welfare, promotes their autonomy to make medical decisions, and the benefits of social justice.[52] These oaths drive the principles in ethics in everyday patient care. If physicians fail to abide by the oaths of medicine, then they fail to meet the moral and ethical principles to care for patients. A medical provider goes into medicine to cure, to help, and to care for others. Promoting the patient's views of quality of life ensures that their care meets all patient values during treatment, interventions, and end of life care.[53]

The patient is the focus in healthcare. Clinical ethics focuses on the patient and makes sure that from the time the patient is admitted to the time the patient is discharged, the stay of the patient is ethically justified. Clinical ethics concentrates on the clinical practices at the bedside.[54] Clinical ethics deals with different concepts of ethics. The concepts of autonomy, beneficence and non-maleficence are the standards of clinical ethics and patient care. The institutional ethics committees analyze the policies of patient's rights and protects the patient's autonomy during any clinical situation.[55] Different committees and review boards have been developed in order for patient care to be handled ethically.

Healing, care, and compassion are some of the most important prefaces during patient care, and without expressed listening and devotion to patients, care becomes a procedure rather than a communicated ethic of systemic caring practices in patient clinical care.[56] Ethics can endorse a higher quality of care if professional staff members are educated enough and open enough to envisioning the patient as a whole entity, learning their story, and configuring the best care for their patient. This care level is

actually reached by understanding patient values rather than a medical objective. Instead of treating patients as a box of malfunctioning organs, medical staff should model a new transformed culture that values compassion and healing with dignity and respect because without those two values, clinical care becomes "heartless", "soulless", and ultimately "worthless".[57]

Ideally if medical professionals could be taught to be ethically and morally just then patient care could always be attained at a just level. However, we do not live in a perfect world and we do not always spend the time or exchange information that can change the care in medicine. We do nevertheless have ethical framework, education, and proactive clinical ethicists to help guide the appropriate medical care for pediatric patients. In the perfect medical world, physicians and nurses would theoretically have a list of each skill, values, virtues that would achieve the desired physician or nurse, and this world optimally attain the goals of ethical medicine.[58]

Teamwork is where ethics starts in the clinical practice. Each member of the clinical team whether it be the secretary that checks the patient in, to the emergency nurse, to the physician on-call, or the transportation staff, each patient deserves that their team strives for success in their patient's quality of care. This team bases their sole purpose on the ethical climate of their clinical setting.[59] The climate of the healthcare organization should promote each staff member to affirm their own moral beliefs and values within the healthcare organization so that they are able to fundamentally employ ethical values in their practice of care.[60] Once clinical staff can use their clinical relationships to "preserve human dignity", innovate incoming staff on the ethical culture,

and change old habits to ensure success for patient healing then quality ethical care will persist to be part of the culture.[61]

A way that can involve all staff members is teaching ethics at the bedside where personnel can experience the ethical issues and solutions in clinical care.[62] The whole team that could range from housekeeping to nurses to physicians can be involved in the educational experience. "Education and collaboration" are a clear connection with medical ethics in patient care and are directly connected.[63] If medical ethics is continued to be seen as education at the bedside then the hospital unit or division will emulate these practices throughout their own care and work. Clinical ethics does not just stop once a conflict at hand is resolved. Staff can mimic these practices and develop a practice that is moral, ethical, and compassionate throughout the patient's clinical experience.[64]

Clinical ethics education will focus on making clinical staff competent by defining the ethical conflict, embracing the ethical culture to devise a clinical defendable opinion, and evaluate the information to make an analysis for a respectable conclusion.[65] Clinical ethics can drive a higher quality of care for the clinical teams, the organization as a whole, and the patient or family. Successful healthcare organizations include clinical ethics that influences the culture and team aspect of the organization so that clinical care is led by the focus of quality patient care that overall supports the patient's overall best interests.[66]

IV.B. Research Setting:

Research ethics is highly important during clinical trials with patients. Ethical issues arise when conflicts of goals and expectations of the research are not met.[67] Patient's may see research as a treatment option when all their other options of pursuing

life are out of reach. This option of research as a treatment are not necessarily true.

Patient's should see research as a trial basis or a last resort to try for different goals in

their treatment plan. This however, should not be seen as a life altering treatment plan,

but rather a hail mary or a means to helping mankind as a whole in revealing other

alternatives to disease in the future. Essentially, research ethics are safeguarding the

vulnerable population from coercion, harm, and exploitation.[68]

Some ethical considerations above and beyond safeguarding the patient pertain to

cultural, religious, ethnic, or gender issues.[69] Initiating research is not only a concern for

coercion or harm it is also a concern for the whole being of the person. Their values just

like clinical ethics are taken into consideration in the research portion of care as well.

Their culture, ethnicity or religion should be made a priority or consideration when

asking a patient to participate in certain research. The patient's culture or religion may

affect their participation in the research. Patients that have different cultural backgrounds

should have solutions and strategies to help the patient better understand the research

process, and the patient should also have the amenities of translators, religious personnel,

or other devices that could help during the preliminary process in research recruitment.[70]

The goals of research from the ethics perspective should be to be beneficent

towards the patient, have respect for all patients, and justice in the respect that all human

beings have rights.[71] This education is far more important than the goals of seeing

effective research. The goal is rather that an un-coerced human understanding the

research they themselves are consenting to understands that this research may or may not

help them or people in the future. The problem with educating staff in research is that

there may be a linguistic gap, a language gap, an IQ gap, a culture gap, a religious gap, a

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conflict of interest, or an age gap.[72] These gaps in education can lead to unethical research without even realizing it. Research needs to be explained just as much as a consent to a surgical procedure. The patient should know the risks and benefits of the research and truly whether the goal of the patient equals the goal of the research study. The quality of medical research can be poor if medical personnel are not educated enough on the ethical principles surrounding a patient being admitted into a study or not having enough concern on whether the medical research candidates or researchers are ethically participating in the study.[73]

The risks and benefits of the research project should be known before the patient is committed to the research, and the medical researcher should be benevolent by using the "do no harm principle" for higher quality in medical research.[74] Members of the research community may not have enough knowledge or furthering education to identify an ethical dilemma during their consent process or during the medical research. It is moderately easy to identify broad ethical conflicts when a person is educated enough to identify them such as: broad inadequate consent, privacy violation, coercion, risk and benefit assessment, or ethical conflict.[75] There needs to be a more invasive document other than the "Nuremburg Code or Declaration of Helenski", there should be a document that protects the research subjects as best as possible based upon their individualized situation that could be adapted by broad questions asked during the pre-trial stages.[76]

Ways that research ethics can be applied and shown to researchers and research departments could be through: empowering employees with up to date ethic rules and education, continuing education with employees so they are aware of the ethics and understand it in current events, and lastly promoting or embracing these ethics values in

their research and conduct research positively throughout the patient's course of care.[77] If preventative actions are taken to educate employees on ethics throughout the research regime, then approaches to research can become more supported by an ethics approach. All healthcare institutions should strive for the highest quality of care in research and to ensure that knowledge and criteria is met they should provide them will the skills of "safety, ethics, and accuracy".[78]

There is a high trust between patients and their medical providers. The information given to patients whether for clinical or research experiences, the medical knowledge should inform the patient of their risks and benefits without persuading or manipulating their aimed goals.[79] Research participants can benefit from educated medical staff on research ethics. Quality of care and reassuring that participants acknowledgement of the research process is taken into an understood consideration that is more than just a signed document. Compassion in understanding the patient's wishes and goals of the research trial or aiding and abetting future research for the sake of other human beings is necessary when dealing with the explanation and throughout the research trial experience. The sought goals should be based upon volition to help oneself or to help others. There should also be a set understanding that the goal achieved is in their best interests with neither means of gain in money or other endorsements. Realistic medical research cases should become a standard in medical education so that researchers are well aware of different ethical dilemmas they may see in the field so they may be able to create a solution while keeping the best interests of the patient at heart.[80]

These areas of research need to be solidified for the quality of ethical research to withstand patient scrutiny in today's society. There needs to be ethical, competent, and

quality standards implemented within the research system. Clinical ethics consultations would be able to provide research staff with the proper ethical education to further quality research. They would also be able to guide researchers through ethical dilemmas and conflicts of interests in the initiation of research and throughout the subject's research trial. These consultants are there for the well-being of the patient subject even though they may not directly benefit from the research trial they are still a priority in the absence of clinical treatment. Ethics consultants then can combine the aspects of compassionate care, effective listening, coordination of care, and conflict management to impose these standards in the pediatric research setting attaining better quality of care from the beginning to the end with the focus on the patient's outlook of research.

V. Prospering Ethics Consultation Education Throughout a Healthcare System:

An ethics consultation service within a health system will provide more than just an ethics consultant that can help in conflicting situations. The consultant will be able to provide ethics education to all staff, provide a consult service, and an ethics committee. Ethics consultation services can be integrated into everyday tasks that will increase the quality of care and overall culture of the organization. The process of full integration of ethics consultations will surpass average care, and provide full integrated quality care that drives compassion and values that medicine needs.

V.A. The Benefits of having an Ethics Consultation Service:

The ethics consultation service will provide ethics education, ethics consultations, ethics rounds, and multidisciplinary ethics committees or rounds.[81] The service will provide an abundant knowledge of ethics education throughout the system. This will be explored not only in the clinical realm, but also in research, the organization as a whole,

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and the administrative areas as well. Ethics does not only include a small sector in a healthcare organization, it actually can intrinsically be adopted into every pillar of the organization's process and outcomes. This way, the healthcare organization will emulate ethics throughout every aspect of care or administrative successes. This education must also promote all healthcare staff to pursue new endeavors as well as being receptive to possibilities of change from ethics implementation throughout the organization to encourage a higher quality in every important decision endeavor.[82]

The division of ethics consultations is one of the most in depth and in person ethics procedures that the ethics service will produce. This service will provide hands on ethics education and ethical solutions to clinical problems in the field. Consultations may be brought on by conflicts of interest, diverging cultural values, confrontation from families, patients, staff, or management of ethical conflicts at hand.[83] Then the ethics consultant will diagnosis the situation as equivalent to a physician diagnosing a disease and give explanations and suggestions to what further course of action should be. Questions from staff can be answered, a sounding board created for innovative ideas that formulate the medical goals with the patient's goals and in turn emancipating ethical dimensions for stronger resources, communication, and effective care.[84] Physicians and other staff members look to ethics consultants as the expert in their field equivalent to their physician counterpart to confirm clinical judgments, and extrapolate a controlled treatment plan based upon the patient's needs and values.[85]

Ethics rounds include a consultant on staff that would participate in medical rounds with physicians and other care providers on the floors that would integrate stronger communication amongst teams, correlated treatment plans, and quality ethical

care. These rounds will discuss the patient's medical needs as well as: spirituality or pastoral care, cultural barriers, legal risks, conflicts, or discussions on end of life care.[86] A recent study showed that ninety five percent of physicians think that an ethics consultation service availability is an important aspect to have and is extremely useful.[87] Many medical students as well as residents would like to see more ethics training earlier on so that they have a grasp of the ethical conflicts arising in their patient's medical care at an earlier stage that can be resolved potentially in medical rounds of patient care.[88]

Multidisciplinary ethics committees not only develop policies, handle compliance issues, "encourage ethical behavior", and promote effective adjustments to previous actions that do not set a high enough bar for quality care[89], but they could optimally be a source for healthcare organizations to develop a higher quality of care and a stronger stance on ethics throughout their managerial, administrative, and non-clinical aspects of operation. The development of a strong ethics committee could then implement integrated committees within the medical specialties, i.e. trauma, medicine, cardiology, neurology, transplant etc.   These embedded committees would create personalized policies, guidelines, and other important resources for the clinical staff to reference in regards to ethics decisions in care based upon their everyday "normal" conflicts.[90]

Ethics education can come in many forms. The consultation service can provide medical personnel and administrative personnel with ethics education through all of these ethics resources. Ethics consultation services can be embedded and intertwined throughout all the networks of the healthcare system so that the quality of care is driven in the most effective way possible. Failed communication, conflicts, consent issues, end of life care options, pain issues, code status and further complicated ethics issues can be

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resolved or focused on by the specialized group of ethics services.[91] Creating and implementing ethics services provides the healthcare system with education, research ethics, clinical ethics, policies, and competence to enable higher quality of care which is the goal of all healthcare organizations to be beneficent until the end.[92]

The problem of healthcare today is that we have become desensitized to our patients. The quality of care needs to be readdressed in today's medicine. Ethics Consultations can benefit hospital systems in five ways: conflict management, quality communication, relief of moral distress, cost reduction, and overall quality improvement. By implementing ethics consultation services within a hospital system, quality of patient care can rise again. The service will in fact benefit the healthcare system and benefit the "consumers" which our patients so desperately deserve. The ethics team can not only provide education, but bridge the quality gap between conflicts, communication, distress, and cost.

V. B. Exceeding Care Limits with Ethics Consultations:

Ethics consultations drive change. An ethics consultation is not one of the easiest aspects of care to explain. How can a system change, if the employees don't understand the change being made? Clinical ethics consultations can be approached at different levels of implementation. The service may be an individual consultant, team, or committee. No matter which type of consult the healthcare organization chooses, the ethical framework and ethical norms will be used within the institutional consultation. The ethical approaches for an ethics consultation can vary depending on which case approach best suits the healthcare organization. The chosen method and approach to

clinical ethics consultations vary on the personality of the organization and possibly each individual consultant, but any approach and method used is appropriate.

An ethics consultation will provide "safe, effective, patient-centered, timely, efficient, and equitable care".[93] This seems as though most healthcare systems already do this, or try to uphold these standards, but as society has shifted and changed, most healthcare systems fall short. It is time to exceed our own limits, and set the bar higher. Most people are influenced by practice, or how they are taught, or what they see, so to influence a new set of standards, we need to connect on a subconscious level that will shape our future actions.[94]

All patient care is expected to be safe. Physicians should weigh the risks and benefits of every possible treatment plan before they offer it to the patient and family. If the burdens outweigh the risks then treatment may not even be considered rather it is in the best interests of the patient if that information is withheld. The benefit should always outweigh the risks and harms for the patient well-being and their best interests. Strong communication of this safety precaution should be taken as well. It is beneficent by those who practice and is standardized from the operations perspective. However, implementing an ethics board like an institutional review board that can overlook policies and procedures to increase benefit and decrease burdens to patients, will then allow the system as a whole to operate at a higher quality of care.[95]

The effectiveness of the healthcare organization is based upon employee attitudes and the culture of the organization. Professional characteristics that drive higher standards and effectiveness in care are taught by emulating the professional teachings of the student that demonstrates compassion, respect, and positive attitudes.[96] New

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employees learn the habits and attitudes of existing employees. If those are low, or falter from the organization's goals and values, the whole system will be on a trend downward towards moral destruction. Moral distress situations could affect patient care, and is usually correlated with moral residue from a buildup of unsatisfied or non-effective care.[97] The effectiveness of patient care is only as strong as the employees that care for them.

Patient-centered care is the commitment or oath that a healthcare organization has taken to institute a quality of care that is centered around the patient from all specialty forces. The healthcare organization goes far beyond the small realm of physician-patient relationship, the faculty as a whole from admissions to discharge only succeeds with passionate driven care. This oversight is heavily influenced by the clinical enterprise that initiates quality care by clarifying processes and procedures, informing patients of diagnostic treatments or examinations, examining the risks and burdens with the patient to ascertain goals of care, and clarifying values or wishes of the patient upon admission if possible or during the course of care.[98]

Timely care is a difficult aspect to access. Time in a healthcare institute is like an eclipse. It is there one minute and then it is non-existent. However, patients need to understand the medical terminology being thrown at them in an instant that may not be digested so quickly. If education was taught in a more palpable way instead of little feedback, and poor demeanors then patients would be able to make decisions in a timely fashion based upon the meaningful standards that physicians hold themselves too when diagnosing and explaining treatment decisions.[99]

Efficiency does interconnect with time. If you have less time, then you are more likely to be less efficient. If you have more time, then you are more likely to be more efficient. However, with less time available, as we have already said that most healthcare institutes wish they could have more hours in the day to effectively get things done, this is not the case and striving for efficiency improvements seem unrealistic and basically unachievable physically to work on within the regular shift work day. Efficiency comes from being innovative, organized, and economic by breaking down negative barriers effecting patient care.[100] This way resources are allocated to reinvent effective communication and improve patient care.[101]

Equitable care should always be a value of the healthcare organization. The four principles that ethics stands on: autonomy, beneficence, non-maleficence, and justice are pillars of this field for a reason. Every patient should receive just, reasonable, unbiased care. Compassion in the field of medicine is required and is expressed in most institutions as a centered value in most mission statements.[102] Ethics services can go above and beyond the norm of medicine. This service exceeds care limits and provides the principles of ethics in real time, real medicine, and for real patients.

VI. Conclusion:

Medicine has become decentered, desensitized, and uncompassionate at times. Medical providers are tired and burnt out or uneducated on how to interact with patients. There is a real problem in the medical field becoming dehumanized. Care and compassion are supposedly one of the most important oaths to medicine. Ethics education, consultation services, and committees can drive the quality of care.

Ethics consultation services will reinvent medicine. The medical institute is an amazing field to be involved in. It is able to help people and harness innovative technology and minds to heal. People enter into this field to make a difference in people's lives.   They are not a failed organ system, they are moms', dads', sisters', brothers', and grandparents of loved ones. These people have names and faces that look to their medical providers for advice and guidance. The healthcare system should be able to provide their highest quality of care available by the education they have been taught. Ethics education will mold the medicine of today into a medicine we as a healthcare institution and as patients of the healthcare system can be proud of. Clinical positions, research, and clinical medicine can learn and be competent in ethics to promote higher quality of care for their patients. Institutions will recognize that embedding ethics consultations and services will promote the new institute of medicine. Higher quality, standardized ethics, and competent medical providers not only will be educated by ethics, but they will drive ethics into a new millennial, a new era of care. Innovative and proclaimed by all.

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