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Children's Autonomy and Medical Decision Making

HALEY THOMPSON

DEPAUW UNIVERSITY HONOR SCHOLAR PROGRAM

PRIMARY THESIS SPONSOR: PATRICIA STAUFFER

COMMITTEE MEMBERS: PROFESSOR JEFFREY DUNN &
PROFESSOR TED BITNER

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1. Introduction

When it comes to medical decision making, there are many elements for a physician to consider. Beyond the physical consideration of the patient's alignment, there are ethical considerations that come into play. These include the principles of autonomy, nonmaleficence, beneficence, and justice. Of these bioethical frameworks, the patient's autonomy becomes a dilemma when working with children. In today's medical system, children are not deemed autonomous to the same extent as well-bodied adults. This becomes an issue when a decision needs to be made regarding a child's health. Whose opinion does the doctor listen to? Does a doctor prescribe medicine to the 14-year-old patient who is asking for birth control without her parent's permission? Does a five-year-old have the right to know of their terminal illness, or should a doctor respect the parent's wishes to keep it from them? Kim Strom-Gottfried (2008) in *The Ethics of Practice with Minors* describes this as, "those who work with minors have an obligation to negotiate both sides of this tension, respecting children's rights and liberties while protecting them from harm" (pg. 61). In these types of situations, doctors should look at the problem from many different viewpoints and formulate as many responses to the dilemma as possible. Then, they need to evaluate the merit of each response, and distinguish which action to apply.

The goal of this thesis is to analyze the dilemmas that arise with children's autonomy when making medical decisions through an interdisciplinary approach with philosophy and psychology.

2. Bioethics and Medical Decision Making

We face ethical decisions in our daily lives in big and small ways. Healthcare, particularly, is guided through moral actions to create the best solutions for patients and caretakers. In our pluralistic society, there are many different values which people hold, which makes the “right solution” not obvious or applicable to every situation. Attempts at guidelines or policies have to encompass consideration for many religions, cultures, and values that people across society hold. Although this is a difficult task, a place to start is to examine bioethics principles and frameworks.

Medical ethics principles have existed for centuries. As early as 4th century BCE, Hippocrates instructed physicians of their obligation “to do no harm” (McCormick, n.d.). In 1979, Tom Beauchamp and James Childress published the *Principles of Biomedical Ethics*, which quickly lead to the spread of using established bioethical principles to guide ethical medical decision making in clinical medicine (McCormick, n.d.). These four principles include benevolence, nonmaleficence, justice, and autonomy.

To start, the principle of beneficence is known as the “do good” principle. It refers to enhancing another’s well-being. At the center of this principle is the notion that a health provider’s goal should be to help the patient. It is not only limited to the individual patient but also applies to the good of society as a whole. For example, an appropriate goal of medicine would be to prevent the future spread of a disease. The principle of beneficence is given priority often in emergency medicine. If the patient is incapacitated by an accident, physicians will

assume that the reasonable person would want to be treated immediately. The following considerations are relevant to treatment options with respect to beneficence (The Medic Portal, 2016): *Is this appropriate to the scale of the problem? Is this compatible with the individual's circumstance? Is this option and possible outcomes in line with the patient's expectations?* The following example from the website, The Medic Portal, describes a situation where this principle comes to light:

“An 8-year-old child has been admitted to hospital with a significant open fracture to their left leg. The limb is deformed with significant bleeding and the patient is extremely distressed. The parents are demanding immediate action be taken.”

In this situation, there are a number of treatments for the doctors to consider. One of these options could be amputation. This would fix the injury and minimize the threat of infection to the wound. However, this would be a life-changing treatment option, which is not proportionate to the scale of the problem. There are other treatment options possible which would not dramatically change the child's physical movement ability for the rest of their life. While beneficence says to promote good, in practice we need to consider the course of action which is best when there are options. What helps with this consideration, is the principle of nonmaleficence.

Nonmaleficence is the “do no harm” principle. It requires that doctors do not intentionally bring harm or injury to the patient. This could be through direct actions or the omission to act. We would consider it negligent to place an unreasonable amount of risk of harm to another. We

would also consider it negligent to not treat a patient in need. This principle emphasizes that doctors have the appropriate skill training and qualifications to treat patients. While nonmaleficence is considered the “sister” to the principle of beneficence, it differs in two ways (The Medic Portal, 2016). According to beneficence, we would consider all treatment options then rank them by order of preference to the situation. Nonmaleficence, acts more as a threshold for treatment. It helps rule out the treatment options by considering the harm and the benefit that can come as a result. Nonmaleficence is also constant, applicable outside of just the clinical setting. Consider the following example, obtained from The Medic Portal (2016).

“A 52-year-old man collapses in the street complaining of severe acute pain in his right abdomen. A surgeon happens to be passing and examines the man, suspecting that he is on the brink of rupturing his appendix. The surgeon decides the best course of action is to remove the appendix in situ, using his trusty pen-knife.”

According to the beneficence principle, the immediate surgery would improve the man’s life. However, we must consider the harms. The risk of infection is high in an unsterile environment, there is no other staff or equipment around if something goes wrong, and the doctor is unlikely to be experienced in performing surgery in the roadside setting. One would deem the risk of harm greater than the benefit in this situation, showing the importance of threshold that nonmaleficence applies.

The principle of justice is most typically defined as a form of fairness. In medical care, this means that individuals in similar circumstances are treated equally. There is also the aspect

of distributive justice which calls for a fair distribution of scarce resources. People's rights need to be respected. In addition, there is consideration of the law and applicable legislation. There are many aspects that can influence the quality of care for a patient and it is important to ensure that no one is unfairly disadvantaged to their quality or access to care. Principles of justice are motivations for reform in our health care policies, to ensure that the entire population is considered.

Finally, there is the principle of autonomy. Briefly described, this refers to the right of the patient to have control over their body. Moral decision making assumes rational agents are involved in informed and voluntary decisions. This implies that patients have the capacity to act intentionally, fully informed, and without controlling influences that would give the notion of coercion or coaxing. I will go into more detail on this principle later.

These principles come with flexibility. They are non-hierarchical, meaning that there is not one principle that is always more important than another. In a case of no competing claims, we have a prima facie duty to uphold all of the principles. However, in reality, there are times when two principles considered in a situation contradict each other. For example, consider a situation where a patient comes in with indications of immediate surgery. According to benevolence, we need to provide the greatest benefit for the patient, and therefore they should have the surgery. However, there is risk of anesthesia and complications of the surgery that must be considered to "do no harm". Here, we can consider the test of rational discourse. What would other people, acting on a rational basis agree with? We must consider and weigh the principles against each other. Does the risk of anesthesia and unknown complications outweigh the risk of

harm if the patient does not go into surgery? W.D. Ross says that prima facie duties are always binding except for the situations where they conflict with stronger duties (Garrett 2004).

Therefore, a physician's actual duties are to weigh and balance all of the competing prima facie duties related to the case. In this situation, it seems that the patient is in much more danger to not undergo the surgery.

While the four principles outlined above guide our moral decision making when it comes to medical ethics, there are also few ethics ideologies that I would like to mention. These ideologies are important to consider when making medical decisions. The first ideology is consequentialism. This is the idea that the "ends justify the means" and that the morality of an action is dependent purely on the consequences. According to this ideology, lying is always wrong. So, if a patient is going into a surgery with low odds of survival, when asked, "will I be okay?", a consequentialism ideology would support the response "no". Another ideology is known as duty based ethics, deontology. This states that action is dependent on your duties and obligations, rather than the consequence. Utilitarianism supports the best action is the one that brings the most amount of good to the most amount of people. This is a form of consequentialism that can be applied to a broader scale, impacting the wider society. This is an abbreviated explanation of the ideologies that can apply to medical ethics issues. However, it is important to consider the different ideologies as they play a role when considering the different principles. They work within the principles to strengthen arguments and help people make the best decisions for a given circumstance. "In addition to giving us tools to assess our choices, these principles, which transcend the helping professions, provide us with a common language to employ in discussing dilemmas with others" (Strom Gottfried 2008, pg. 21).

In reality, there are many factors that play a role in clinical settings for decision making. Amount of resources, insurance, accessibility, professional abilities, and more, all impact the quality of care for a patient. These ethical principles are applied to different situations to determine action, but frequently with quick actions and short deliberation. While reality ensures pressures outside of our control, it is these ethical guidelines that create the foundation of work as a health care practitioner. They help practitioners justify their choices and communicate to others. They are used when mistakes occur to fix practices in the future. Practitioners make decisions that determine who has care, what kind of care they receive, who decides the treatment, what risks are too great, and more. This responsibility is not taken lightly.

Before moving on, I would like to demonstrate an example of a case study where physicians apply the mentioned principles. Consider the following case study written by Ralph E. Kauffman (*abbreviated from the original*):

“TJ is a seven-year-old boy who was diagnosed with asthma at three years old. His asthma is of moderate severity and is well controlled with medications most of the time, although he has occasional exacerbations requiring a visit to either his physician or to the emergency room. Otherwise, he is healthy, attends school regularly, and participates in sports. TJ’s asthma medications include a daily use of a corticosteroid inhaler and use of a bronchodilator inhaler as needed for worsening of his asthma symptoms or before physical exertion.

TJ and his parents have been approached about his participation in a clinical study of a new medication for asthma to assess its safety and efficacy in treating children with asthma. It has not yet been studied in children, but three studies have been completed with 550 adult patients with asthma. The preliminary evidence from the adult studies is that the new experimental drug does improve asthma in some patients and has very few side effects. The side effects so far in adults have been occasional nausea, headache, and dizziness. However, these side effects occurred at about the same frequency in adults whether they were taking the experimental drug or a placebo.

If TJ participates in the study, he will be on the study protocol for a total of fourteen weeks. During weeks three through fourteen, he will be randomized to receive either his standard treatment, the experimental drug plus the bronchodilator inhaler as needed, or a placebo plus his bronchodilator inhaler as needed. While he is on the study, he may not use any drugs for asthma other than those mentioned above. The evaluation will require six additional visits to the physician's office where breathing tests will be done and blood will be drawn.

The details of the study have been explained to TJ and his parents and they have been asked if they and TJ will agree for him to enroll in the study.”

As we analyze this medical decision being made by TJ's parent's and doctors, first it is important to consider the possible risks and benefits of enrolling in the study. Risks include the listed side effects, unexpected side effects, taking TJ off of his corticosteroid, not being able to use other asthma related drugs if needed, his asthma could get worse, increased exposure to

disease with more doctor's visits, and stress. Benefits include improved asthma symptoms, assisting the study to enable more people to access the drug in the future, and the possibility of unexpected positive side effects. Following the benevolence principle, it would be the right thing for the doctor to recommend the treatment. If TJ's current asthma medication is not benefitting him enough, this option might be a better course of action. But, if TJ's current medication is benefitting him and allowing him a comfortable life style, it is possible that the risks outweigh the benefits. Considering the principle of justice, by contributing to this study, he is contributing to the possibility of the drug to be used by more people in the future. In order for TJ and his parent's autonomy to be respected, it would be important for the researchers to disclose all information that they had from previous studies, even the most unlikely side effects.

Because TJ is only seven, he is not allowed by law to independently consent to medical care or agree to be in study. Do his parents have a right to volunteer him to be in the clinical study? Does TJ have any rights? Should he have the right to volunteer or refuse to be in the study against his parent's wishes? Now comes into consideration the question of autonomy for TJ. If TJ were your child, would you give permission for him to be in this study? Would you ask him before you made your decision or after?

3. Autonomy

By law, TJ's parents are the legal decision makers for TJ. They can decide for TJ to be a part of the clinical study or not. They will need all of the information about the new drug, recent studies, and any other relevant medical information to have all of the information to make the decision. They must not be under pressure or have undue influences effecting their choice. This then, by most standards, would be deemed autonomous. What I want to point out is TJ's role in the decision-making process. His parent's decision to enroll in the study or not will have the most direct impact on TJ's life. Does he have a substantial presence in the decision? Should he? In general, to what extent are children-patients made a part of making medical decisions related to their own healthcare?

We must begin with the consideration of what the principle of autonomy is and what it means to be an autonomous decision maker. In medicine, a patient's autonomy is representative of their freedom of choice. For a healthcare provider, respecting patient's autonomy means respecting patients who have decision-making capacity to make their own decisions regarding care, even when it contradicts the doctor's suggestions. Tom L. Beauchamp and James F. Childress talk about autonomy as a central principle in *Principles of Biomedical Ethics* (2001). Autonomy, according to them, requires both liberty and agency. By liberty, they mean independence from controlling influences. By agency, they mean the capacity for intentional action (Sedig 2016).

For medical practice, Beauchamp and Childress suggest that the phrase “respecting autonomy” embodies the task at hand. They say that there are three moral requirements of respect for autonomy, being “...choosers who act (1) intentionally, (2) with understanding, and (3) without controlling influences that determine their action” (Beauchamp & Childress 2001, pg. 59). They say that intentionally cannot be to a degree, but is either intentional or nonintentional. However, the following two conditions, can be to a degree. “Many children and many elderly patients, for example, exhibit various degrees of understanding and independence found on this continuum and thus varying degrees of autonomous action” (Beauchamp & Childress 2001, pg. 59). For a person to make a choice autonomously, they must have only a substantial degree of understanding, not a full understanding. However, where the line of substantial and insubstantial lies, they admit is arbitrary (Sedig 2016).

Beauchamp and Childress make a point to acknowledge the limitations that this definition of autonomy seems to imply and they argue for a more realistic application. They describe it as the following, “We aim to construct a conception for respect for autonomy that is not excessively individualistic (neglecting the social nature of individuals and the impact of individual choices and actions on others), not excessively focused on reason (neglecting the emotions), and not unduly legalistic (highlighting legal rights and downplaying social practices)” (Beauchamp & Childress 2001, pg. 57).

The first point that they make here is about individuality and the social nature of individuals. According to previous claims, to make a decision autonomously, one must not be coerced or unduly influenced. The call for what is coercion and what is not could be a hard line

to establish. While it is a priority for patients to make their own decisions, they are also members of families. Decisions that patients make will go on to impact the lives of their family members. Patients, naturally, often wish to take their family member's opinions into account when making their own medical decisions. Respecting autonomy then means that doctors must respect how patients wish to make their own decision, even if this decision is to allow their family's wishes to influence them. While it is ideal that family members have the patient's best interests at heart, in reality, this is not always the case. This is not to imply that family members intend to harm the patient but what they want might not be the best choice for the health of the patient. In other words, family members could be suggesting a second-best choice for the patient that benefits themselves more than the first-best choice would be for the individual. A strict definition of autonomy that doesn't recognize an individual as part of a family would be an incomplete understanding of decision making (Sedig 2016).

Another aspect that Beauchamp and Childress mention is that being autonomous does not exclude considering emotions. One could challenge the proposed model of an individual with a rational will as neglecting to acknowledge the role that emotions have in ethics. This notion that being emotion is irrational and emotions obstruct one's judgment is present in philosophical history. Immanuel Kant rejected sentimentalism as a base of moral decision making because of the following concerns: "one is that emotions are volatile (what one feels today one may not feel tomorrow); two, the capacity for sentiment is not evenly distributed (and thus those who exhibit sympathy may act more morally by inclination than those who do not); three, for these reasons a sentimental ethics is not universalizable – one cannot establish thereby ethical laws" (Donovan 1996, pg. 82). This creates the conception that emotion is irrational and uncontrollable. This

conception has been challenged by philosophers who say that being emotional actually carries a cognitive element. For example, H.B. Acton in “the Ethical Importance of Sympathy” (1955) argues that sympathy, used interchangeably with emotionally, is a “form” of rationality (Donovan 1996). Max Scheler says that true understanding comes from both intelligence and emotion. “Scheler does not, therefore, see sympathy as a whimsical, erratic, and irrational response, but rather as a systematic investigatory tool, a form of knowledge” (Donovan 1996, pg. 85). Sympathy theorists go so far as arguing that sympathy is necessary for ethical decision making. Emotions do not limit our ability to make decisions or create an irrational will. We should not view emotions as an obstacle to autonomous decision making, but embrace the morality that they bring.

As we move on to discussion, I would like to provide a basic definition of autonomy for reference. Autonomy from now on, when used, will be in reference to, “a person’s ability to make his or her own decisions, including those affecting medical care. Respect for autonomy requires the recognition of a person’s right to make independent choices, and take action based on personal values and beliefs” (Cooper 2005). So, why is autonomy important? Immanuel Kant said that respecting autonomy recognizes that all people have unconditional worth. To not respect someone’s autonomy, would be to treat them merely as a means. John Stuart Mill said that we must not interfere with other’s freedom of expression while expressing our own individuality but that we can seek to persuade others when we disagree with their views (Strom-Gottfried 2008). Medicine is one of the most intimate practices and places patients at one of their most vulnerable places. The human body is not just anatomical parts connected through tissues and blood. The human body is composed physically, mentally, and emotionally into a being. The

task that doctors have places the patient at the will of the doctor. Doctors can prescribe an antibiotic to beat a sore throat but can also over prescribe an antibiotic that leads to antibiotic resistance, leaving the patient susceptible to worse, life threatening diseases. This cause and effect relationship between the doctor's actions and the effect on the patient's effects is evident. For medical practices to be grounded in moral ways, the patient must feel as though they have some form of control. The requirement of respect for autonomy protects the patient and the doctor.

Just because this principle is deemed necessary, doesn't mean that the world is perfect and that respect for autonomy is always upheld. Even if someone is autonomous, this doesn't mean that they will act autonomously. For example, when someone signs a consent form without reading it, they are failing to act autonomously on their own doing. One's autonomous choices can be overridden by competing moral considerations. With respect to utilitarianism and the greater good, if choices endanger the public health or lives of many, one can justifiably restrict their choices. Another appropriate example would be if a patient requested a treatment that requires a scarce resource where limited funds are available (Zolkefli 2017). "Physicians and other health professionals do not have the authority to declare patient's incompetent as a matter of law, but, within limits, they often have the de facto power to override or constrain patient's decisions about care" (Beauchamp & Childress 2001, 69). Doctors do have the ability to deem a patient unable to make their own decision about treatment. This override's the individual's autonomy for the sake of their own well-being. In a sense, doctors play this role to protect patients from themselves. People make wrong choices. Even though choice seems intrinsically good and is valued, this does not guarantee that the outcome is to benefit.

At this time, I would like to bring back up TJ, the seven-year-old from the case study earlier who's facing the choice of joining the clinical trial for asthma medicine. Alone, TJ is not granted the ability to make this decision for himself. The primary impediment to this ability are the current policies in place related to minors and healthcare decisions.

4. US Law and Medical Decisions

In the US, for the majority of states, when a patient is under 18 the physician must obtain consent from the patient's parent or legal guardian. Minors are deemed incompetent to give legal consent. Parental consent is the ability to allow or refuse medical treatment for a minor.

There are a few exceptions that give some minors the right to consent in specific situations. One of those exceptions is in emergency situations. If the minor's life is threatened and a parent or guardian is not present to give consent, consent can be presumed. This will only be for cases where delay in treatment would cause serious harm to the patient. For any ongoing treatment after, consent must be obtained (McNary 2014). Another exception is if the minor is emancipated. For example, according to Arizona Law A.R.S. § 44-132: "Any emancipated minor, any minor who has contracted a lawful marriage or any homeless minor may give consent to the furnishing of hospital, medical and surgical care to such minor, and such consent shall not be subject to disaffirmance because of minority. The consent of the parent, or parents, of such a person is not necessary in order to authorize hospital, medical and surgical care" (Schoolhouse Connection 2019). If the minor is legally granted emancipation, therefore living independently without support of their parents, they are granted the same legal rights as an adult. They can consent and refuse medical treatment. Another exception for minors is related to the type of treatment sought. For certain circumstances such as drug abuse, alcoholism, pregnancy, contraception, mental illness, sexual assault, or domestic violence, minors are allowed to get treatment without parental consent. These cases will differ for individual states and for most

states, there is the additional requirement to be above the age of 14 (Schoolhouse Connection 2019).

Then, there is the case of “mature minors”. Mature minors are un-emancipated individuals who are deemed able to make their own medical decisions. This resulted from the court case of *Smith v. Seibly* (1967). In Washington at the time, the age of consent was 21 years. 18-year-old Albert G. Smith received a vasectomy after finding out he had a muscular disease and then sued his doctor with the claim that they failed to inform him of the permanency of the treatment. The Supreme Court at the time ruled that Smith had the mental capacity to consent and given his life circumstances (married, held a job) he was competent to make the decision (Feldmann 2015). Thus, came the mature minor doctrine. This doctrine requires “youth to demonstrate an understanding of the relative risks and benefits of the proposed treatment” (Strom-Goffriend 2008, pg. 51). There is not a developed set of factors to determine if a minor is “mature” or not, instead the individual is evaluated based on their specific circumstance for a specific treatment. Assessment typically considers living arrangement, marital status, cognitive levels, maturity, independence, and economic stability. This has been used in cases where treatment refusal by the parents is not the best option for the child. Mature minor declarations are made related to a specific treatment. It is unlike emancipation which grants a minor independent in multiple situations. The treatment must be established to be of benefit to the minor, does not present a high level of risk, and is in the range of the established medical options (Post 2017).

A controversial example of application of this doctrine is the case of 17-year-old Cassandra C. She was diagnosed with Hodgkin’s Lymphoma, which has a chance of survival of

85% if treated. However, Cassandra wanted the choice to forego chemotherapy and so her legal counsel asked the state of Connecticut to adopt the mature minor doctrine. This request was denied by the Supreme Court of Connecticut because Cassandra was deemed not mature enough to make her own medical decisions. They did not specify why exactly they made this claim except they did report numerous actions of Cassandra running away from home to avoid treatment. Cassandra's doctors had earlier reported her mother to Department of Children and Families (DCF) for child neglect so Cassandra was placed under state care. Cassandra had to wait until she turned 18 until she could make the choice to forego treatment (Feldmann 2015). Cassandra's case shows how difficult it is to achieve mature minor status. Some may argue that at 17 years, one has the cognitive ability to understand the entirety of the diagnosis and treatment options. Cassandra had even written an editorial for the *Hartford Courant* where she explained how she was mentally and emotionally exhausted and did not want to go through with chemotherapy. She says, "this is my life and my body, not DCF's and not the state's. I am a human – I should be able to decide if I do or don't want chemotherapy. Whether I live 17 years or 100 years should not be anyone's choice but mine" (Cassandra, C. 2015).

These laws and policies have been developed to protect individuals. Some populations are ultimately considered more vulnerable than others. This can be due to age, cognitive abilities, education, legal status, and more. Children are specifically seen as a vulnerable population. In general, there is the notion to protect the future of the child. "It almost goes without saying that the figure of the child is conceptually bound to notions of futurity (Berlant, 1997; Edelman, 2004; Spivack, 2004; Munoz 2009; Berland, 2011; Mollow 2012). This sentiment is repeated time and again in our culture; we hear it in song lyrics (e.g., Whitney Houston's declaration, "I

believe that children are our future/teach them well and let them lead the way” [Masser and Creed, 1984) and political speeches (e.g., former president John F Kennedy’s famous pronouncement that “children are the world’s most valuable resource and its best hope for the future” [Kennedy, 1963, para.1])” (pg. 119, Mc Guire). In general, children are dependent on their care takers for their basic needs. This vulnerability stems from their evolving capacities (Strom-Gottfried 2019). They are continuously developing physically, emotionally, and cognitively. At some points of their development they are more capable to make decisions about their health care.

There are some flaws in the current policies that the US holds around medical care and minors. While the intent to protect the vulnerable group of children, in general, it fails to recognize minors as independent decision makers about their own health care. To start, the current laws do not acknowledge that a disagreement between a legally competent person (such a parent) and a minor about a minor’s healthcare treatment is an issue. It assumes that the parent or guardian’s decision will consistently trump the minors. This absolute authority gives the notion that children are property of their parents. The law also does not require involvement from the minor in the decision-making process. While involvement is typical, this is not always recognized as an obligation that health providers must follow. The providers who do act on this are not always supported.

US policy related to healthcare gives so much weight to the age of 18. At this point, minors assume adulthood and all of the responsibilities that come with it in a clinical setting. If we propose a model that replaced the age based qualification, how will this affect other laws?

Will there need to be a new standard for when we can drive, drink, vote, or buy cigarettes? There is a possibility that this will be an opportunity for discrimination to occur. Some people with mental disabilities have already lost their right to vote because of competence laws. 13 states have laws that stop individuals from voting who are “under guardianship”. For example, a person could be put under guardianship during a psychiatric crisis. However, this does not automatically deem them incapable of understanding elections (Roth & Zabel 2018). The benefit of using age as the determining factor is that discrimination could be minimized.

Within the law, there are currently two standards for informed consent in medical practices: physician-based and patient-based. About half of the states use the physician-based stand. This is in reference to other physicians. It is described as, “A physician ‘has a duty in the exercise of ordinary care to inform a patient of the dangers of, possible negative consequences of, and alternatives to a proposed medical treatment or procedure’ [8] with the same ‘degree of skill and diligence exercised by a reasonably prudent practitioner in the same field of practice or specialty’ in the same state” (Weinmeyer 2014). The patient based standard “requires a physician to disclose any material risk to the patient, meaning the physician believes a reasonable person in the patient’s position “would be likely to attach significance to the risk...in deciding whether or not to forego [sic] the proposed therapy” (Weinmeyer 2014). These standards primarily arise in medical malpractice cases. It shows how there is ambiguity around what needs to be disclosed and how to measure the accuracy. Patients and physicians will frequently disagree about what risks they consider important or not. There is not a single standard of care but instead variations.

There are instances where the parent gives informed consent but that decision is not considered the “best interest” of the child. “Best interest” is defined as, “surrogates making such decisions should choose so as to promote the patients interests as they would be conceived by a reasonable persons when in the patient’s condition” (Center for Bioethics n.d.) In other words, it is tailored not to the individual, but how a reasonable person would act. The Healthcare Treatment Decision-Making Guidelines for Adults with Developmental Disabilities goes on to advocate for actions which relieve suffering, preservation of function, and the quality of life to be considered (Center for Bioethics 1996). Parents are expected to provide for their children and are entrusted that their choices ensure the well-being of their child. Parents are given liberty to decide for themselves, according to their own values and beliefs but can still be challenged when the doctor feels for the well-being of the child. An example to consider is following case:

“Larry is a 12-year-old who was struck by a car and has been brought to the trauma ER. There, it was discovered that he has a severe renal injury with significant internal bleeding. When his parents arrive, they tell the physicians that, because they and Larry are Jehovah’s Witnesses, transfusion of blood or blood products is out of the question. How should the religious convictions of Larry’s parents influence the decision about his receiving potentially life-saving blood transfusion? What weight should be given to Larry’s religious beliefs?” (Post 2007)

This is a case where the question becomes if the child’s interests trump the parent’s authority? Doctors have a responsibility directly to their patient and in this case, the nonmaleficence principle would guide the physician’s choice to refuse the refusal of care. While these instances are rare, they do occur. Court intervention will grant the override of the parent’s decision

authority. Courts tend to rule for life-saving interventions, even if the treatment is painful and marginally effective (Farber 2007). Larry's parents are capable adults and if this was them in the situation, they are able to accept the risk of their religious commitments for themselves. A child is not deemed mature enough to accept those same risks and so the court steps in so that his life is not at risk. It is important to note that Larry is 12 years old. If he was a little older, it is possible that he could formulate a conviction worth considering respect of his religious based wishes. Decision making capacity would then need to be recognized.

5. Decision Making Capacity

When I was younger I hated getting shots. My mom would take me to the doctors for my yearly checkup and when the time rolled around that the nurse came in with the tray of syringes, I was ready to bolt. I would cry and resist the nurse because I did not want to receive the shot. As my mom constrained me in her arm with promises of ice cream if I held still, the nurse plunged the syringe into my small arm. One might say in this instance; my personal autonomy was violated. However, despite my clear ability to communicate my wishes this does not mean that I had the judgement for medical decision-making abilities. So, what deems an individual as having decision making capacity for healthcare practices?

Decisions with healthcare are a big deal for everyone. The stakeholders include the physician, the patient, the families, the hospital or institution, and possibly others. Healthcare decisions will impact a person's everyday life. "These decisions involve deeply personal ideas about life and death; the meaning of health, illness, and disability; and the importance of self-image, self-determination, and trust" (Post 2007, 24). There are many things that can influence this process and therefore, the result of the decision. Physician-patient communications are critical. Ideally, the patient feels comfortable talking with their doctor. Notions of trust, understanding, and openness help guarantee better outcomes for the overall experience. How the physician presents information to the patient, the language they use, and how much information they provide matters. The patient should feel open to ask questions and be genuine with their responses. Physicians should also respect the patient's values and preferences and the patient

should likewise show respect for the physician. This relationship is important for all of the stakeholders.

What needs to be established in this relationship for treatment to occur is informed consent. In general, informed consent is defined as when a fully informed individual, with decisional capacity, can participate in making health care decisions. They must be determined as a competent and voluntary agent. They must have information about their condition and prognosis, understand the intervention, and be able to understand the risks, benefits, and side effects (Center for Practical Bioethics, n.d.). For minors, this consent is given by parents because minors are considered incompetent. The term competence is the legal determination that a person is at a certain age and can make judgments for appropriate legal tasks. “In medical contexts, for example, a person is usually considered competent if able to understand a therapeutic or research procedure, to deliberate regarding its major risk and benefits, and to make a decision in light of this deliberation. If a person lacks any of these capacities, then his or her competence to decide, consent, or refuse is thrown into doubt” (Beauchamp & Childress 2001, pg. 72). In other words, legal competence is dependent upon decision making capacity.

Decision making capacity is the ability to exercise autonomy by making decisions that reflects an individual’s preferences at a given time (Post 2007). This is the clinical determination of the ability to make decisions. Decision making capacity enforces autonomy and requires moral responsibility. Moral responsibility of the patient is “to be accountable for his [or her] actions and suggests qualities of stability, consistency, and foresight” (Post, Bluestein, Duller 2007, pg. 67). Determining capacity for making medical decisions is difficult for patients of any

age. Doctors encounter this dilemma when working with patients who might be experiencing dementia, are disabled, or patients in a confused state. In order to propose the notion that some minors should have the ability to consent to their own medical treatments, we must break down what capacity consists of.

Two elements that are continuously expressed as a dimension or criteria of showing capacity for making health care decisions include evidence of reasoning and understanding. Understanding and reasoning refer to the ability of the patient to comprehend their condition, the treatment, the risks and benefits of the treatment, and how it would affect their lives and those around them. Assessing a patient's understanding is not a simple true false quiz. In fact, "empirical studies often fail to provide data that can illuminate how much patients and subjects understand" (Beauchamp & Childress 2001, pg. 90). These studies focus on memory and recall which cannot adequately reveal what patients understand when making a decision. Yet, the physician has to ensure actual comprehension. This could be shown when the patient describes the information in their own words as opposed to repeating exactly what they were just told. This could be measured by the follow-up questions that the patient asks. It comes more from discussion than a formal survey. In some cases, even a single detail missed could limit a person's adequate understanding. It is necessary for patients to share an understanding with the physician each step in treatment. To help this, physicians can use specific language and vocabulary. "Many conditions limit their understanding, including illness, irrationality, and immaturity" (Beauchamp & Childress 2001, 88).

Even if a child seems able to understand and can articulate the proposed consequences of a treatment, this does not guarantee that they have been able to grasp this as a reality. A true appreciation of experience is from direct experience itself, which minors lack compared to adults from limited time and exposure of life experiences. Nonetheless, even adults are poorly able to predict their feelings and responses to situations that are so far different from the current (Strom-Gottfried 2008). For instance, a child with a chronic medical condition that has experienced multiple painful treatments is more fit to predict the pain, discomfort, and reality of treatment procedure than an adult without any hospitalization experience.

Another example of how to assess decision making capacity is described in the *Handbook for Health Care Ethics Committees* written by Post et al (2007):

“The cognitive tasks include the following:

- Understanding and processing information about diagnosis, prognosis, and treatment options
- Weighing the relative benefits, burdens, and risks of the therapeutic options
- Applying a set of values to the analysis
- Arriving at a decision that is consistent over time
- Communicating the decision”

Post suggests evaluating these with the method called “the sliding scale”. This method correlates the level of capacity required with the gravity of the treatment at hand and the impacts

that will arise from it. When there are higher risks with the treatment, the higher the level of capacity is needed.

Similar to Post, in *Healthcare Treatment Decision-Making Guidelines for Minors*, it says that decisional capacity should be assessed “in relationship to each particular treatment decision”. Therefore, a child could have been deemed capable of making a decision for one treatment but not another. At minimum, it should be determined that the minor has reasonable understanding which is defined “a level of understanding that meets his or her needs in the decision-making process, regarding

- The nature of his or her health problem
- Treatment options and their potential benefits and burdens
- The consequences of treatment options, including no treatment

The minor must also be able to

- Think about options and reach a conclusion that reflects his or her values
- Communicate the decision to caregivers (verbally or nonverbally)”

They note that certain treatments require a greater certainty about the capacity of the minor than “routine treatments” which seems to match the method of the sliding scale. While this analysis is valuable for a case by case basis, it seems difficult to implement in real life settings where doctors are limited by time and resources. Every case will be different and have complicated factors to consider which are nearly impossible to cover in entirety. There are serious dangers to making mistakes when determining decision making capacities. “Excluding a decisional capable patient from making choices violates autonomy; treating an incapacitated patient “as if” she was

capable makes her vulnerable to the consequences of deficient decision making. Thus, the clinical assessment of decisional capacity is critical to determining whether the patient can participate in care decisions and provide informed consent and refusal” (Post 2007, 25).

Another danger of the sliding scale approach is the tendency for paternalism. “In ethical terms, paternalism represents the opinion that beneficence is a higher value than autonomy; a situation can occur in which paternalistic behavior is ethically permissible” (Zolkefli 2017). It is easy to question someone’s capability especially when we do not agree with their decision. This can lead to violating someone’s autonomy when in reality they had the full understanding and reasoning abilities for decision making. In the medical setting, minors do not have the legal authority to make their own decisions and therefore are not expected to. In most cases, physicians enter a room with a minor accustomed to not giving minors a consideration for capacity. This calls for the need to reset how physicians consider the status of children. In addition, we must take the time to distinguish between questioning capacity and finding incapacity.

6. Developmental Theories

These skills of understanding and reasoning and therefore, decision making capacity, are linked to the developmental capacity of the child. “Developmental considerations are central to ethical decision making with minors. Going beyond mere chronological age, evaluations of a youth’s cognitive functioning, judgement, and maturity determine the extent to which he or she is capable of making a reasoned decision; anticipating the import of various choices; and generating acceptable options. These and other elements of competence affect the degree to which a minor might be included in decision making and the degree to which his or her decisions should sway” (Strom-Gottfried 2008, pg. 26). Instead of using age as a qualification, levels of development could be a better determination of where a child stand’s in their ability to be included in health care decisions. Studies of human development are understood by perspectives of many theorists. Developmental theory is defined as, “a systematic statement of principles and generalizations, providing framework for understanding how and why people change over the lifespan” (Berger 2016, pg. 23).

Choices are an important part of children’s development. They can develop decision making skills when asked what they want to eat for lunch or what they want to wear that day. This helps them develop their own reasoning, individuality, confidence, and expression of themselves. The consequences for these choices are minor compared to the impact that healthcare ones can have. However, being neglected from the process of choice in healthcare can also be harmful. This can be disempowering and lower a child’s confidence in themselves. Cooperation between the patient and provider develops trust in the relationship. This will follow

after the direct treatment and the patient will be more likely to follow the doctor's advice, therefore, leading to better health outcomes (Zolkefli 2017). Involvement in the choice will help individuals rebuild body image and sense of self-determination, especially after life changing treatments (Farber 2007).

According to Kathleen Stassen Berger, there are four different characteristics of human development. It is important, as we take into the consideration the different theories that apply to the developmental context, to recognize what defines development as a discourse. Development is characterized as being multi-directional, multi-contextual, multi-cultural, and plastic. Development is not linear but will change. People will experience gains and losses and unexpected growths will occur at any age. Development is multi-contextual, meaning that there are many different influences. You cannot pinpoint a person's growth to biological or environmental reasons, but it is a mixture of all of their experiences. Health practitioners must take all contexts of their partners lives into consideration when treating them. Some examples include historical conditions, economic constraints, and family patterns (Berger 2016). Cultures will affect people's values and how they develop. Further, change is plastic, or otherwise said as ongoing and neither random or predictable.

There are significant physical, emotional, and cognitive differences from minors and adults. The types of theories of development that demonstrate these differences are broken into the following categories: psychoanalytic, cognitive, and social learning.

Psychoanalytic theory is a theory of development which claims that unconscious drives and motives, often originating from childhood, explain human behavior (Berger 2016). When we look at the work done by Sigmund Freud, he focused on the early childhood experiences and how they impact stages of human development with a psychosexual theory. He portrayed childhood growth as age-related periods of development, each with its own defining characteristics. He classifies his stages into five different steps: oral (birth to one year), anal stage (one to three), phallic stage (three to six), latency (six to eleven), genital stage (adolescence), and then adulthood. Infancy, or the oral stage, is the time of most vulnerabilities. The child is completely depended on their caretaker. All of a child's desires are oriented around lips and mouth. The anal stage is forced around the pleasurable sensations of the own baby's body, usually around toilet training. Phallic stage is defined by pleasure from genital stimulation. These preschool years Freud hypothesized was when penis envy came to play a role in the children's life. It was a sense of pride for males and resulted in envy and sadness for the girls. Latency stage is defined as a "quiet period" where children repress earlier desires and learn the reality-principle. The genital stage is around puberty, where young people seek sexual stimulation and desire for members of the opposite sex. He said that these sensual ratifications were linked to developmental needs and conflicts. How people went about conflict resolution defined them in their personality and explain behaviors later in life.

There is much criticism around Freud's work. He was sex focused and his scientific research methods are controversial and unreliable. While we can recognize the disparities in his theories today, his psychoanalysis was monumental to the study of developmental psychology. His framework of stages and how each stage builds on another, influences how we view

development. We recognize that development is not an isolated instance but influenced by experiences throughout our lives.

Erik Erikson is another example of stage-dependent theorists where he identified eight different psychosocial stages of development. He characterized each marked with a crisis between individual growth and societal supports and struggles. These stages included, trust vs mistrust, autonomy vs shame and doubt, initiative vs guilt, industry vs inferiority, ego-identity vs role-confusion, intimacy vs isolation, generativity vs self-absorption, and integrity vs despair (Berger 2016). These stages go from infancy (age 0-1) all the way to old adult (age 50 and above). “For Erikson, the ever-changing developmental landscape requires that the practitioners assess emerging physical and psychological capacities from the perspective of “maturation” or movement through life stages, which involves adapting and responding to new psychological and social challenges” (Strom-Gottfried 2008, pg. 53). He recognized that the realities of these conflicts were not the exact polarities as he defined. Instead, outcomes between the two opposites are likely. Both Freud and Erikson believed that childhood conflicts will go on to impact adulthood. Erikson’s stages differ from Freud’s by being family and culture centered rather than sexual.

Another form of developmental theories is called cognitive theories. These ask the questions: How are they thinking? Are they able to understand? Are they able to reason? The theories focus on how children think and organize knowledge. These include skills such as reasoning, problem solving, and memory. “We can expect younger children to be knowledgeable about the concrete issues related to their decision, while adolescents may be able to understand

the more abstract factors that a frame decision-making contexts or processes” (Strom-Gottfried 2008, pg. 58). Similar to psychoanalysis theories, cognitive theories develop in stage-dependent steps.

Jean Piaget is an example of a cognitive theorist. His central thesis of cognitive theory was that, “how people think (not just what they know) changes with time and experience, and then human thinking influences actions” (Berger 2016, pg. 29). He wanted a way to explain how children acquire knowledge and on the nature of intelligence. He believed that as children interacted with the world, children obtain knowledge and build on existing knowledge. He was the first to recognize that children think different (not less intelligent) than the way that adults think (Wadsworth 1989). He proposed that intelligence is something that grows and develops in a series of stages. The factors of schemas, assimilation, accommodation, and equilibration influence how children learn and grow. A schema describes the mental and physical actions that are involved in understanding and knowing. It is a category of knowledge and is the process of obtaining knowledge. As experiences happen new information is used to modify, add to, or change existing schemas. Assimilation is the process of taking in new information to what we already know (existing schemas). This process can be subjective because we tend to modify experiences and information to fit our pre-existing beliefs. Accommodation is adaptation to our existing schemas. This modifies ideas as a result of new information and new schemas can be developed during this process. Equilibration is when children try to find a balance between assimilation and accommodation. In other words, they try to maintain a balance between applying previous knowledge (assimilation) and changing behavior to account for new

information (accommodation). Equilibration helps explain how children move from one stage to the next (Wadsworth 1989).

Piaget identified four cognitive structures that children progress through. Sensorimotor stage, age birth to two and preoperational stage (age three to seven) focus on intuition and immediate sensory experiences. Concrete-operational (ages eight to eleven) and formal-operational stage (twelve to fifteen) focus on an understanding based on objective and logical mental processes (Berger 2016). Application of these stages and Piaget's cognitive theory is used to develop growth standards for children.

There are currently 11 different cognitive tests for assessment of decision making capacity which assess for the four components (understanding, reasoning, appreciation, and expression). The major issue in creating these assessments is if there is standardization or tailoring to the relevant issue at hand. Standardization would help validate the assessment when comparing the data. Lack of standardization affects inter-rater and test-retest reliability. Yet, standardization is difficult to truly apply to the nature of the different contexts of clinical decisions. This decision making skill is, “an inherently context-specific construct referring to the individual's capacity to make a choice about the specific decision at hand ([Dunn, Palmer, & Karlawish, 2007](#); [Grisso & Appelbaum, 1998a](#))” (Palmer 2016). There were four models which assess not with standardization including the MacArther competence Assessment Tool for Treatment (MacCat-t), Competency Interview Schedule, Structured Interview for Competency and Incompetency Assessment Testing and ranking Inventory, and Capacity Assessment Tool (Palmer 2016). Among these four, the MacCAT-T is the most popular and seemed to have the

highest reliability and validity in contexts. However, there is still a lack of data showing the frequency in which these assessments are used in clinical settings.

Models used to assess capacity of decision making for minors are critiqued for being too cognitive focused (Palmer 2016). Issues such as authenticity, values, and emotions seem to be neglected in the current forms of assessment. Thus, it is almost important to consider theories of social learning.

Social learning theorists emphasize that relationships in a child's life will impact growth and skill in an ongoing series based on learning experiences. The child's development is continuous and nonlinear influenced by interactions with cognitive, behavioral, cultural, and environmental influences. It stems from behaviorism, which is defined as theory which studies observable behavior and describes the processes in which behavior is learned (Berger 2016). A key difference between psychoanalytic theory and behaviorism is the importance of childhood. Psychoanalysis says that childhood is critical and that the conditions during this time will define a person for the entire life. On the other hand, behaviorism says that current conditioning is critical. It argues that behaviors are not permanent and can be re-learned or re-taught. A direct example of this is the idea of conditioning. Created by Ivan Pavlov, he created the idea that conditioning is a process which responses are linked to a stimulus. This classical conditioning lead to the explanation of operant conditioning which explained that a response can change depending on if what follows the stimuli is desired or a punishment. A major theorist in this field is Albert Bandura. He created the social learning theory which says that social interactions influence other people's behaviors. He distinguished four interdependent processes in human

behavior: attention, retention, motivation, and motoric processes. These processes were thought interact with the environment. Changes in the environment are expected to change the way a person behaves and what they believe. Similarly, changes in belief can refigure how one interprets their environment (Brainerd 1983). This shows the important of how context can affect someone.

These different frameworks demonstrate how measuring development comes in a multitude of contexts. Children's timeline of development will vary based on environment, exposure, genetic dispositions, and more. The way that we measure this development is different for each theory of study. However, when practicing with children, it is essential that we consider all of the frameworks and how they build on each other to impact the child.

There is also criticism of the use developmental theories in general. In the book, *War on Autism*, Anne McGuire writes, "Developmental psychology, and its central tool of observation and measurement, the continuum of normal human development, produces normative divisions among individuals where by individuals (both the advocate and the advocated for) must either fall within the borders of the normal or are excluded from these borders" (89, McGuire). She argues that these studies are harmful to minority groups and marginalized populations such as those with disabilities. These theories create a standard of what "normal" is and looks like which can create unfair treatment to individuals who differ. "Rose underscores that this popularization and wide dissemination of the normal developmental continuum changes how we orient to the bodies of children, how we see them and read them and therefore how we treat them" (88, McGuire). Our treatment of children needs to differ from our treatment of adults. These

developmental theories help distinguish this and the many components of how they are different. Yet, it is important not to over generalize these developmental theories to effect and influence how we view a child's worth.

7. Applications

The Center for Practical Bioethics in Kansas City, MO, has created a handbook called the Healthcare Treatment Decision-Making Guidelines for Minors. In this handbook, they describe three different categories which provides a model for the types of decision making capacities. These include minors without the capacity to participate in decision making, minors with a developing capacity to participate in decision making, and minors who have the capacity for most healthcare decisions. Each comes with different responsibilities for the minor, parent, and health care provider.

What underlies their model is the notion of child assent. This is a child's expression of willingness to undergo a healthcare treatment. This is based on the child's knowledge and understanding of the situation. The process for soliciting this includes steps of assisting the minor to understand their situation, disclosing prognosis and future experience, and ensuring that the minor is not under coercion. The model proposes that healthcare providers who are obligated to receive informed consent from a patient's parents must also obtain the child's assent. This recognizes their developing capacity for their participation in decision making without giving the child too much power. This model also rejects the concept of parental consent and instead, they propose informed parental/guardian permission. Their definition of informed consent included:

“a person with decisional capacity, or his or her personally designed surrogate, authorizes treatment. Consent must be given voluntarily and without coercion based on a clear understanding of at least the following:

- The nature of the patient’s condition and prognosis;
- The nature and purpose of the proposed treatment; and
- The benefits, risks, and burdens of the proposed treatment alternatives or nontreatment.”

The definition they provide for informed parental/guardian permission includes:

“a process by when the parents or guardians of minors grant or deny permission to the provision of recommended healthcare interventions for their children or wards.

- Healthcare providers have obligation to obtain parental permission prior to healthcare interventions (except in emergency situations)
- Informed parental permission involves all the “informational” elements of informed consent.
- Parents may give permission or refuse to give permission to initiate or terminate healthcare treatments when minors are unable to participate in decision making.
- Informed parental permission must be coupled with the assent of the child when decisions involve a child with a developing capacity for decision making”

The authors admit that this model is a suggestion and not a recommendation of policy. They call their model a shared decision-making model. It provides the child a shared opportunity in the decision-making process with consideration of how a child’s assent adds to the process. It recognizes children as independent decision makers but still gives authority to the parents for the final say. This additional step is crucial to better respecting children’s autonomy in medical decision making.

Within their three different categories that minors fall under, the first is those who do not have any decision-making capacities. This includes those who are unable to make or communicate treatment decisions, such as infants or preschoolers. They suggest for these cases that decisions are made based on the “best interest of the child standard”, made by the parent.

The second category is minors who have a developing capacity for decision making. In this category, they suggest explaining clearly to minors that they have the right to help their family and doctor in deciding treatment. It explains that they can communicate in agreeing, disagreeing, asking for help in the case of disagreement, or asking for clarification.

The third category is minors who have a capability for decision making. This suggests that minors are free to express their own personal, cultural, and spiritual values and beliefs when considering which treatments to be done. They have a right to all medical records and information contained in them. They have a right to know all information about the treatments or diagnosis including nature and purpose, benefits and risks, likelihood of success, and alternative procedures. They have the right to personal privacy and confidentiality from their parents.

This model does a good job of including a child’s opinion in the decision-making process. They also make an important point that there are degrees of gravity which each treatment holds, and therefore capacity needs to be determined in each circumstance. This nonbinding label for the child will help ensure their protection in situations that have more

serious consequences than others with treatment. A child could not be deemed “decision making able” in a routine checkup where they are getting a shot and then continue holding that label when they are asking to refuse a chemo treatment.

However, the model lacks in clarification when describing how to assess decisional capacity. They do not explain how to distinguish between developing and having decision making ability. Even with the ones that do have decision making ability, there seems to be levels within this, depending on the treatment. What levels of understanding are non-negotiable? How do you determine what information is crucial to the situation and what information is okay to not understand? Can you really test for if a decision reflects a person’s values or not?

In addition, the way that the guide proposes to distribute this document is through the form of informational brochures at healthcare programs or facilities. They say that one standard for determining if a patient is in the category of “developing capacity” is if they could read the brochure. While this may seem like a logical requirement, those who are preschoolers or infants in the category of no capacity could not read it, it also is limiting. Minors with learning disabilities or cognitive disabilities would not be considered. Those who are blind, speak another language, have not been taught how to read, and others could be cast out. This requirement seems to be excluding the vulnerable of the already vulnerable population that they are attempting to protect. In addition, they suggest a list of rights to be read to the patient. This seems to be intimidating and fear invoking. While it is important for a child to know that they have the right to voice their opinion, to use phrases like “the right to get angry, cry, or say what you don’t like about what is happening to you” suggests that this situation will occur.

Anthropologist Myra Bluebond-Langer suggests a model where the physicians and parents have prior conversations about diagnosis and care options, before beginning a conversation with the child-patient. The goal of this is to ensure children are involved in the decision-making process in a way that does not expose them to too much. This method is focused on, “the recommendation of recognition and respect for the reality of children’s relation to their parents and other adults” but ensures that the child’s “inability to control the process has not kept [them] from being an active player” (Ford 2017). While attempting to give the child a larger stakeholdership, this further protects the relationship between the parent and physician. Those who have the possibility of making their own medical decisions, such as adolescents, could be further removed from the possibility.

A single model of assessment for determining decision making capacity has yet to be applied and practice with consideration of minors in healthcare. It is important to protect children but recognition of their abilities to decision making will help them in the future. Physicians must consider where the child is developmentally when determining this and how it is relevant to the particular clinical context.

Conclusion

The way that the US grounds its healthcare policies and practice are in bioethics approaches as opposed to human rights approaches. With autonomy in medical decisions being dependent on age for minors, questions arise regarding children's general stakeholderhood and agency in their ability to make medical decisions. Children are placed in a "liminal space" (Ford 2017) between childhood and adulthood. Aiden Ford says, "Rather than held from birth and bestowed by virtue of a common humanity, rights become an object to be awarded when patients meet certain moral and cognitive criteria of competency and patient-hood". Physicians, parents, and policy makers ultimately, want to protect children. They want to ensure the best possible future for them by assisting them with some of the hardest decisions to make. This form of protection is important but also can be limiting. The question of balance between autonomy and risk is one engrained in our current healthcare system – and one worth examining for the future of the child.

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