

THE MATURE MINOR DOCTRINE: THE ETHICAL DILEMMA OF  
RESPECTING ADOLESCENTS' RIGHT TO REFUSE CARE

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## ABSTRACT

The mature minor doctrine legally allows minors with the maturity of an adult to make decisions about their medical treatment, sometimes without the knowledge of their parent or guardian. However, the mature minor doctrine does not live up to its expectations; there are no guidelines for determining if a minor is mature or if the minor has the capacity to consent. The court system's reluctance to allow minors to refuse treatment, the focus on stereotypical adolescent behavior, and the possibility of penalization of the family also serve as drawbacks to minors exercising their right to bodily autonomy through the mature minor doctrine. Standardization can solve these issues, revolutionizing the mature minor doctrine so that minors' preferences about their care, particularly in the setting of life-threatening illness, can be honored.

## DEDICATION

For Ella;

A bright and brave teenager  
who was going to change the world,  
but definitely changed me.

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## CHAPTER 1: INTRODUCTION

Seventeen; that is how old Cassandra Callender was in 2014 when she was diagnosed with Hodgkin's Lymphoma. After receiving several rounds of chemotherapy, Cassandra failed to go into remission; it was at this point that she, with the support of her mother, decided to stop pursuing further cycles of chemotherapy. Even with the knowledge that Hodgkin's Lymphoma has an 80% cure rate with standard of care therapies, Cassandra did not want to poison her body; she knew that there were possibly long-term toxic effects from using chemotherapy, which included leaving her prone to developing other cancers later in life (Briggs 2015). She wanted to try "alternative" treatments and she understood that refusing chemotherapy meant there was a possibility that she could die. This is when the legal system became involved; the hospital where she was being treated in Connecticut contacted the Connecticut Department of Children and Families, or DCF, for suspicion of medical neglect. Legal custody was taken from her mother and given to the DCF, which led to a lengthy custody battle. Eventually, the Connecticut Supreme Court ruled that Cassandra did not meet criteria by the mature minor doctrine to legally refuse treatment. One of the factors that played a role in this was that she had at one point run away from home to avoid treatment, demonstrating her supposed immaturity; in reality, running away was likely a result of Cassandra's desperation to be heard and fear of what would happen if she was not. Cassandra ended up being held in the hospital for 5 months against her will, unable to contact with her mother or return home, so that she could receive intravenous chemotherapy despite her objections. Not only was she not listened to by her doctors or the court system, but she was forced to receive treatment because it was in her "best interest". The commissioner

of DCF recognized the trauma this experience caused Cassandra and her family, but still said, ““We want her to complete her treatment so that she can return home knowing she has put this completely behind her”” (Briggs 2015). Only, she did not put this completely behind her; her cancer returned. Cassandra died in May 2020 at the age of 22 from her Hodgkin’s Lymphoma.

While there was a brief period of time in which Cassandra’s cancer was in remission, how could one forget being sedated to receive treatment they opposed and unable to have their support system present as they traversed one of the most frightening and vulnerable times in their life? There is no doubt that the loss of a young person is tragic but ignoring their wishes and actively forcing them to receive care they do not agree to is a tragedy unto itself; it betrays the ethical concepts of non-maleficence and agency, which are just as important to uphold in minors as it is in people who have reached majority. If this case happened when Cassandra was 18 years old, there would have likely been a very different outcome, as we respect the bodily autonomy of individuals once they are adults. But being a minor does not mean they should not have input into what is happening to their body, particularly if they are able to understand the risks, benefits, and consequences and verbalize their concerns and wishes. As a pediatrician-to-be, I have a vested interest in ensuring that my patients and their families have space to advocate for their health and agency in their decision-making as it pertains to their care, especially in the setting of medically complex situations such as life-threatening illness. Cassandra’s case demonstrates how the medical system in collaboration with the legal system can mandate medical decisions irrespective of the wishes of the adolescent or their family and this is done by denying the adolescent meets

the standards set by the mature minor doctrine, if the state even has the mature minor doctrine as a law. My goal for this paper is to provide context to the mature minor doctrine and its faults, examine the standards in defining capacity and the mature minor, and explore other cases that utilized the mature minor doctrine, before concluding with suggestions on how the mature minor doctrine can be improved.

## CHAPTER 2: THE MATURE MINOR DOCTRINE

Before going into depth about the mature minor doctrine, it is important to have some historical context regarding it and the refusal of life-sustaining medical treatment. “The competent adult patient has the right to refuse any medical care, including life-saving treatment; [meanwhile] minors are presumed to be incompetent because they lack decisional capacity and their parents have surrogate decision-making authority” (Talati and Lang 2010, 126). Yet, adults did not always have the explicit right to refuse medical care in the setting of terminal or life-limiting illness; in fact, it was a “Supreme Court ruling in 1990 of *Cruzan v Director, Missouri Department of Health* that determined the Constitution would grant a competent adult the right to refuse life-sustaining medical care based on the Fourteenth Amendment” (Driggs 2001, 694). And “[w]hile children have constitutional rights, they are not equal to those of adults as the governing bodies view children as vulnerable and typically unable to make mature and reasonable decisions in serious or critical situations” (Driggs 2001, 693). This is why parents, the surrogate decision-makers for a child who is unable to do so themselves, are held to a best interest standard, which states that there is a presumption that the parents know what is best for their child, but the state also has a vested interest and therefore the authority to intervene when parents’ decisions fall short of the threshold (Driggs 2001; Ross 2009). However, this becomes complicated as children grow older and enter the adolescent years; that is where our story regarding the mature minor doctrine begins.

The mature minor doctrine is a rule that legally allows minors who are deemed to have the maturity of an adult to make decisions about their medical treatment that traditionally have been reserved for persons who have attained the age of majority,

sometimes without the knowledge of their parent or guardian (Weithorn 2020; Raftery 2015). The precedent of the mature minor doctrine was first established in the United States in the 1967 case of *Smith v Seibly* in the state of Washington (Raftery 2015). In 1961, Albert Smith, a then 18-year-old married man and father presented to Dr. Walter Seibly for a vasectomy. The patient had a diagnosis of myasthenia gravis; the progressive nature of the disease concerned Mr. Smith about the impact it would have on his wife and family. He decided a vasectomy would be most beneficial and consulted Dr. Seibly. At the time of this case, the age of consent was 21, so Dr. Seibly told Mr. Smith and his wife to go home, discuss the benefits and risks of the procedure, which included permanent sterilization, and return with a signed consent form if they decided to proceed with the procedure. Mr. Smith returned with the signed consent form and the vasectomy was performed. However, when Mr. Smith reached the age of majority, he sued Dr. Seibly for medical negligence, performing the procedure on a minor without explaining its permanence, and failing to receive valid permission. The case came to the Washington Supreme Court, which rejected Mr. Smith's argument and stated, "[A]ge, intelligence, maturity, training, experience, economic independence or lack thereof, general conduct as an adult and freedom from the control of parents are all factors to be considered in such a case" (Smith v Seibly 1967). They further went on to state that, "The mental capacity necessary to consent to a surgical operation is a question of fact to be determined from the circumstances of each individual case" (Smith v Seibly 1967). As we can see from this case, the original adoption of the mature minor doctrine was to eliminate legal liability of health care professionals when treating minors in circumstances in which their parent or guardian is unavailable or unwilling to consent (Weithorn 2020). While this was

typically applied in the setting of non-serious cases for older adolescents, there has been a shift recently for the mature minor doctrine to be applied to serious cases, typically in the setting of life-threatening conditions such as cancer.

Currently, there are three instances in which parental consent can be waived in medical treatment of minors. The first is in an emergency, which is defined as a condition that requires urgent attention or is causing a child pain or fear; the idea for care in emergencies is that if the parent was present, they would have consented to the child receiving treatment. (Slonina 2007; Driggs 2001). The second instance is if a child is emancipated, which includes the child being married, enlisted in the military, or economically self-sufficient. In this instance, parental consent is waived because the minor already operates totally independent from their parents; therefore, they should be treated as an adult (Driggs 2001). The third way is the mature minor doctrine, which requires the court to be petitioned to determine if the minor truly has full comprehension of treatment and consequences (Driggs 2001). The ways in which the mature minor doctrine is commonly used by the United States, which is embedded in the states' statutes, is to provide minors access to services related to contraception, prenatal care, abortions, outpatient mental health and substance use treatment, sexually transmitted infections, and sexual assault (Slonina 2007; Weithorn 2020). There are several reasons why the medical concerns previously outlined are ones in which minors are given independent access to treatment. One major reason is that these concerns delve into sensitive matters that minors are often hesitant to disclose to their parents because it can create conflict between the child and parent, especially if the child experiences opposition to their treatment choice or fear negative repercussions. Another major reason is that

there is a broad societal agreement and substantial scientific evidence as to the benefits to the minors and society facilitating these services. If these conditions are not treated, there would be a negative impact on the United States' public health; this was seen in the epidemic of sexually transmitted infections in the adolescent population during the 1960s, which led to minor treatment statutes, allowing access to reproductive health treatment without parental consent (Driggs 2001; Slonina 2007). Finally, there is constitutional, policy, or other considerations that increase the significance of supporting minors' decisional autonomy in some of these treatment contexts (Weithorn 2020). It is important to note, these exceptions to parental consent and conditions outlined above do not involve the possibility that death of the minor will be a result of treating without a parent or guardian's approval (Driggs 2001).

While all states have some semblance of the mature minor doctrine as it pertains to mental health, substance use treatment, and reproductive health, the mature minor doctrine is a statute in only 21 states in addition to the District of Columbia. Even in these states, there is no standardization of the law which creates substantial variation, particularly in the determination of maturity (Weithorn 2020). In fact, there are so many things to consider to determine if a minor can be declared mature, as we will discuss later, that a well-reasoned, unambiguous, and uniform standard has failed to emerge with no movement to clarify or simplify the rule coming from either the medical or legal system (Slonina 2007). The mature minor doctrine is also only explicitly laid out for minors to consent to treatment; only three states, Massachusetts, Illinois, and Virginia, have explicitly stated minors can refuse care without parental consent (Driggs 2001; Raftery 2015). Why haven't more states made the mature minor doctrine a law? I was

given insight into this while talking with Chief Attorney in the Parental Defense Division of the Maryland Office of the Public Defender, Nena Villamar. We discussed a case that she had in the appellate division with a background similar to that of Cassandra. Maryland's Child Protective Services opened a case of medical neglect against a middle class black family for declining cancer treatment for their son. The reason for the treatment refusal? The 16-year-old patient's commitment to his religion and spiritual well-being; he viewed his body as sacred and did not want to introduce toxins to it, even with the understanding that if he did not receive chemotherapy and radiation, he would die (Hall and Villamar 2021). Instead, the patient wanted to explore the option of homeopathic treatment. To him, his spiritual being was more important than his physical body, as he believed that after death, we exist in some other form. As Maryland is one of the states that has not adopted the mature minor doctrine as law, this would have been the opportunity to advocate for the implementation of it, especially since Maryland allows adolescents to make mature decisions, such as consenting to sex and dropping out of school, at the age of 16 (Hall and Villamar 2021). This was not what happened, however, as the case ended up being nullified, meaning that it was not on record. While the mature minor doctrine is becoming more relevant as more adolescents are opposing medical treatment, the adoption of it by a state typically requires a prominent case to push it to the forefront of hot topic issues. During trials, lawyers will refer to established laws from other states to prove their point. The court can adopt the law for the state or make this an issue the legislative body must resolve, which is typically how a bill is introduced (Hall and Villamar 2021). As the case in Maryland was nullified, there is currently no reason for the state to consider making the mature minor doctrine a statute. In the states where

there is currently no mature minor doctrine statute, the state has no reason to show significant state interest in intervening in the privacy right of the minor if there are no active cases that pertain to the subject (Driggs 2001). Yet, without an established standard, the issue ends up having negative consequences down the road for minors trying to exercise their right to bodily autonomy.

As we have explored the history of the mature minor doctrine, how it is used, and how it is made a state law, we have not yet discussed the major pitfalls of the mature minor doctrine. The major issue with the mature minor doctrine that has been alluded to previously, is that “state courts have been inconsistent in their decisions when it pertains to a minor rejecting life-sustaining treatment, and in most states, unemancipated minors are not afforded the right to make their own medical decisions” (Driggs 2001, 701). In the cases in which “refusals have been respected, those decisions are based on the premise of developing autonomy of certain mature minors and required parental support, indicating that parental influence is a prominent factor” (Talati and Lang 2010, 127). For the “court to support a mature minor’s right to refuse treatment, it had to be weighed against ‘four State interests including preservation of life; protecting the interests of third parties; prevention of suicide; and maintaining the ethical integrity of the medical profession’” (Slonina 2007, 191). But what we have seen is that the courts are “notoriously inconsistent in the use of the standard of proof that is required for application of the mature minor doctrine”; this is likely due to the fact that “[they] are reluctant to apply the mature minor doctrine in cases of life-threatening situations, even when the child has the support of the parent” (Driggs 2001, 696). Why? Because if a judge allows a child to stop life-sustaining treatment, it is a death sentence; something

that judges often do not have to rule on, especially when it comes to minors as it goes against the concept of protecting children's best interests (Driggs 2001). Another issue that is associated with the mature minor doctrine is what happens to families if the court does not rule in favor of the minor. For the patient, this may mean having medical care forced upon them; patients are likely to be non-compliant in response to this, which could present with patients fleeing, being rejected by family, or avoiding medical care in situations they need it due to the lack of trust (Caplan 2007). Obviously, this is not something that anyone would want to do because of the trauma and disruption of stability the patient experiences. Meanwhile, the parents who supported their child in refusing medical care experience a different type of consequence. "When parents refuse life-saving therapy, they are failing to promote their child's basic medical needs, which has to be prioritized over other interests and needs of the minor and family" (Ross 2009, 310). It is at this point, especially if clinicians believe there is a good prognosis or the refused treatment is known to be effective, that "the refusal is viewed as child abuse or neglect, which prompts the legal system to step in" (Ross 2009; Talati and Lang 2010, 126). One thing to note is who the charge of medical neglect affects more; Villamar has seen this charge more frequently in lower socioeconomic and ethnic minority families than she has in more affluent, white families. After the charge is brought against the parents, physical custody will be taken or they may only have limited guardianship, which requires a third party to make decisions regarding medical treatment or surgery. This custody can be returned if the needs of the state are met. However, if parents are found to be guilty of civil or criminal medical neglect, they are then put on a central registry, as is federal requirement, which stays with them, impacting their ability to get certain jobs as it will

show up on a background check (Weithron 2020). Practicing their right to refuse medical care should not lead to oppression of minors and their families, yet we see that is precisely what can happen. The fact that families continue to rely on the mature minor doctrine even with this potential risk to themselves demonstrates their respect for their child's right to bodily autonomy. The first step for us as a society to respect this is to be transparent about our definition of a mature minor.

### CHAPTER 3: DECISION-MAKING AND THE MATURE MINOR

As demonstrated throughout the last chapter, there are many areas in which the mature minor doctrine and its implementation require improvement. One aspect of the issue is the lack of definition for “mature minor” with decision-making capacity and competency as additional factors that are not fully conceived for children, particularly adolescents; without a coherent definition of what a mature minor is, there is a struggle to determine what should be highlighted when considering decision-making capacity. Another issue that complicates this is the concept of shared decision-making; there is no definitive explanation for what this really means or the criteria by which to judge what falls within or outside the boundaries of this model (Charles and Gafni 1997). The triadic relationship in shared medical decision-making for pediatrics, particularly as the minor becomes older and has a greater opinion about what they want, which may differ from that of their parents, can create certain tensions that the mature minor doctrine must address (Ruhe et al 2014). And the final issue that comes with the application of the mature minor doctrine relates to who is given the duty of deciding who is a mature minor. To sum it up plainly, the crux of the issue with the mature minor doctrine relates to the concepts of capacity and consent.

Before going into depth about how we allow minors to participate in decision-making, it is important to understand different medical decision-making models and their pertinence to the mature minor doctrine. The idea of shared decision-making grew out of the increase in patients experiencing chronic illness that 20 to 30 years prior would not have survived (Charles and Gafni 1997). Shared decision-making is especially important in potentially life-threatening illnesses, such as cancer, as there are key decision points

that may happen early on or only once in treatment; “they cannot be delayed without potentially serious implications for health of the patient” (Charles and Gafni 1997, 682). One of the older models of decision-making is the paternalistic model; in this, the patient has a passive role in treatment decision-making with the physician as the expert in the medical encounter using their skills to decide upon the best course of action (Charles and Gafni 1997). “The extreme version of this is the physician telling the patient what intervention they will have; the physician serves as the guardian of the patient’s best interests without eliciting the latter’s preferences” (Charles and Gafni 1997, 683). The constrained parental authority model mirrors the paternalistic model, replacing the physician with the parent and the patient with the child with a caveat; parents have the authority to make medical decisions for their child, but it is constrained by the respect owed to the child (Ross 2009). The role of the parent is to make sure their child’s basic needs are met and that they are aiding the child in the development of skills necessary to both becoming independent and making autonomous decisions, while also taking into consideration the child’s own present and future goals (Ross 2009). These two models are in juxtaposition to the informed model; here, information is shared from the physician to the patient, allowing for control to be vested in the patient as they can take this information with their preferences to decide on the best course of action, empowering them to be a more autonomous decision-maker which is achieved through self-development (Charles and Gafni 1997; Gorgos and Ghosh 2019). The implementation of the mature minor doctrine as it pertains to a minor’s desire to refuse care is a clash between all of these decision-making models; the paternalistic view of the medical system knowing what is in the best interest of the minor, the violation of the constrained

parental authority of the parent if they support their child, and the desire for informed consent from the minor who wants to claim their bodily autonomy by making decisions about their care. It is here that determining decision-making capacity to ascertain the type of participation the minor should have is warranted.

Understanding decision-making capacity requires understanding the levels of participating in medical decision-making; four exist. “These four levels include being informed, expressing a view, influencing a decision, and being the main decision maker; children’s level of participation should be informed by their abilities and preferences” (Ruhe et al 2014, 779). The latter two levels reference the difference between the capacity to assent and consent, respectively. “Informed consent occurs when a patient has been given all of the information regarding their illness and all possible options in treating said illness before deciding the best course of action” (Slonina 2007, 199). “Assent, on the other hand, occurs when the patient agrees to a course of action decided on by a third party, with the third party deciding on a course of action after receiving all the information on the patient’s illness and all possible treatment options”, with the parent serving as the third party (Slonina 2007, 199). “Having the capacity to assent indicates the patient, typically a minor, has sufficient competence to have some appreciation of a procedure but not enough to provide fully informed consent” (Foreman 1999, 491). In order to do this, the minor must have “awareness that permission for the proposed action be sought independently, an understanding of what is being proposed, and an ability to make an independent choice free from outside influences” (Ruhe et al 2014, 780). However, what is essential about assent is that it needs to be perceived as a steppingstone in minors developing the capacity provide informed consent; this is

necessary for it to carry value in informing appropriate participation in medical decision-making (Ruhe et al 2014). A minor's decision-making capacity is constantly developing as opposed to being stagnant like most people believe; therefore, it is crucial to continually evaluate it to ensure it harmonizes minor participation in their care with their emerging capabilities (Ruhe et al 2014). Legally, patients are not able to provide informed consent until they reach the age of majority at eighteen (Slonina 2007). Having the capacity to assent, on the other hand, has been granted for older minors, starting around 12 years of age (Talati and Lang 2010; Foreman 1999). While we have informed consent and having the capacity to assent as ways for minors to interact with making decisions, the next step is to establish what attributes we are looking for in minors to allow them to progress from providing assent to fully informed consent.

How do we define a mature minor? The term maturity has not been made clear in any of the mature minor statutes; "sometimes it is synonymous with competence and other times it is a broader standard referring to social, emotional, and psychological factors beyond such treatment competence" (Weithorn 2020, 29). "The lack of standard means there is no consensus about the standard's meaning, allowing for a greater likelihood that it will serve as a repository for unstated values of the evaluators; a narrower meaning would allow the standard to be more easily utilized and better able to assess minors' decisional capabilities" (Weithorn 2020, 30). So again, the question is, how do we define a mature minor? "The most revered researcher in the area of child cognitive development was Jean Piaget, whose theory proposed four stages of development based on knowledge that develops and increases until it reaches a point where it is fully effectual" (Driggs 2001, 703). These stages are influenced by self-

learning and education, with the final level occurring between the ages of 11 and 15; it is at this point that the child can engage in independent thought, draw deductions, and understand theories (Driggs 2001). This gives them the ability to “imagine past, present and future conditions of a situation, hypothesize how the situation might occur in different conditions, and solve problems by applying theories” (Slonina 2007, 194). What is lacking from this theory thought is “the effect of other people or the environment on the behavior of the child” (Driggs 2001, 703). It has been found that adolescents are more likely to engage impulsive behaviors with focus on immediate consequences; however, “the older the adolescent, the more consideration they give to risk and future consequences” (Foreman 1999; Driggs 2001, 704). In fact, “empiric data has been found to suggest that there is no qualitative or quantitative difference in cognitive skills between most minors in mid-adolescence and adults”, with the decision-making process of 14-year-olds comparable to that of adults (Sigman and O’Connor 1991, 522; Driggs 2001).

While knowing that 14-year-old’s have decision-making skills equivalent to that of adults, we still have not yet defined what the medical and legislative bodies care about when it comes to granting minors the ability to take a more active role in the decision-making. Before delving further into this topic, I want to explain the difference between capacity and competence. “Capacity is a person’s cognitive ability to manipulate information in order to make decision, whereas competence refers to the authority of a person to transform such choices into legally binding decisions within the limitations of the law” (Ruhe et al 2014, 777). Why do we need to differentiate these two terms? For pediatrics, it is crucial to keep these terms separate because while children do not generally have the right to make legally binding decisions, they may consent if they are

found to have decision-making capacity; having capacity does not automatically lead to competence in minors (Ruhe et al 2014). Yet, determining capacity looks very different when examined from the perspectives of the courts versus the medical professionals. The court system seems to be most preoccupied with “a comprehensive list of characteristics [...] to determine whether a minor had the capacity to agree to any medical treatment: age, ability, experience, maturity education, training, and demeanor [with] these factors taken in the context of the whole medical situation, including the ability of the minor to understand the treatment, the risk, and the consequences” (Slonina 2007, 190). Medical professionals, on the other hand, have three distinctive tenets that must be met before it can be said that a patient has the capacity to provide full consent: understanding, reasoning, and voluntariness (Slonina 2007). Understanding refers to having the ability to appreciate information relevant to their illness and the offered treatment; reasoning means being able to process the information they have been given to consider the long-term effects of the illness and treatment; and finally, voluntariness, which indicates there is an absence of undue influence on the decision-making process from fear, pain, false beliefs, or false information (Slonina 2007; Ruhe et al 2014). A minor typically can demonstrate their mastery of first two elements of determining capacity by the age of 12; it is voluntariness that tends to not appear in adolescents until the age of 14 (Slonina 2007). Obviously, these skills evolve with maturation and experience of the minor; this requires physicians to constantly engage with children in process of decision-making to assess their readiness for taking a more active role in their health care (Ruhe et al 2014).

There is no question who decides if a minor is mature; when pediatricians and the patient disagree about the best course of action, particularly as it relates to a life-

threatening condition, the pediatrician will refer to the court system to resolve the issue. When the legal community is brought into the picture, there is “no effort to incorporate any medical concepts on maturity or show a correlation with medical opinions and policies on respecting a minor’s right to choose their own path of treatment when ill with a life-threatening disease” (Slonina 2007, 205). “It is difficult for judges to uniformly apply the concepts of knowing, intelligence, and voluntariness in a uniform manner to cases involving the mature minor doctrine because the stage of development of the child cannot be fully known by the judge”; judges are expected to “evaluate valid scientific information presented about child development and then render what is believed to be an ethical decision that will govern the life and/or death of the child” (Driggs 2001, 712). Instead, the judicial system is presented with opinions of others about the minor, giving them an incomplete perspective portrayal of the minor. “From the cases that have received appellate review, it appears that trial judges determine the maturity based on their perceptions of a child’s demeanor during testimony” (Slonina 2007, 206). It feels unreasonable to allow a judge to make such a monumental decision because they do not know the child, their behavior, their environment, or their current versus preferred quality of life well enough, even with the assistance of existing but inconsistent expert testimony (Driggs 2001). Then who should have the ability to decide who is a mature minor? “The medical community’s policies on a minor’s consent and bioethical guidelines place the physician in the best position, as compared to a judge or the parents, to gauge the minor’s maturity” (Slonina 2007, 185). As we explained previously, the judge does not have the scientific reasoning nor a standard to abide by to make this decision; meanwhile, the concern with parents is that they cannot estimate the quality of life for their child, and

they may not be able to accept when a child has reached their limit because of the particular grief tied to loss of a child (Gorgos and Ghosh 2019; Seller and Rasmussen 2019). A pediatrician not only has the factors previously discussed, but they also "...have medical training and experience that comes with their profession; overall, they have more tools to determine the maturity of the minor than any other party who would be involved in life-sustaining medical treatment decisions" (Slonina 2007, 185). It is the job of the pediatrician to promote the minor's mental and emotional development, evaluate their level of maturity, and support the independence after they have ascertained they are able to consent (Slonina 2007). "This great responsibility of [facilitating the self-determination of the adolescent] is difficult in these cases because they must, at a tragic time, make this judgment of the minor that is free of their own values and interests" (Slonina 2007, 201).

## CHAPTER 4: THE MATURE MINOR DOCTRINE IN PRACTICE: OTHER NOTABLE CASES

As we have seen so far, the major issue with the mature minor doctrine is determining whether the state has a compelling case in mandating that the adolescent seek medical treatment, which is based on the perceived competence of adolescents to make informed and sound health care decisions on their own (Steinberg 2013). Prior to Cassandra's case, there have been several other cases regarding patient refusal of medical treatment in the setting of life-threatening illness, some of which had drastically different results than her case, while others had results that mirrored hers. This discrepancy in how these cases were handled makes sense, as "ethicists have agreed that individual decisions should be made based on the maturity of the adolescent and balanced with the nature of the medical decision" (Sigman and O'Connor 1991, 522). I believe it is important to examine other mature minor doctrine cases as well to have greater context for how the state handles these cases. The cases in which I have chosen to explore not only had a significant impact on the mature minor doctrine in the states which adjudicated them, but they also had greater impact on how the mature minor, the right to refuse medical treatment, and the right to die was viewed within the ethics community.

The first case that I want to discuss is that of Starchild Abraham Cherrix, a 15-year-old boy from Virginia. Abraham was diagnosed with Hodgkin's Lymphoma in 2005 at the Children's Hospital of the King's Daughters in Norfolk, Virginia. His doctors recommended chemotherapy, which left him bald, feverish, nauseated, and weak. Within 2 months of completing treatment, he had a recurrence of his cancer and was told by his oncologist that he would need to undergo another course of chemotherapy in addition to

radiation, which statistically had a 90% success rate after completion of 3 rounds. Abraham, now 16 at this point, with the support of his family refused the treatment recommended by his oncologist. Instead, he traveled to Mexico with his father to receive the Hoxsey treatment, an American folk remedy created in 1920 that is a mixture of plant and root extracts that was later condemned by the FDA in 1956 (Caplan 2007). However, a clinic existed in Tijuana that was run by a nurse who worked with Hoxsey and could provide the treatment. By 2006, physicians reported Abraham's parents to social services for medical neglect and social services determined that Abraham was not receiving adequate care. The case went to court with the suggestion that parents relinquish custody so Abraham would have to receive chemotherapy and radiation; there was a stay from Virginia's circuit court, which later ended up with Abraham's parents being cleared of all charges. Abraham was able to continue receiving the Hoxsey treatment in addition to radiation under the purview of an oncologist (Caplan 2007; Ross 2009). When Abraham reached majority, he did end up receiving standard medical therapy of a stem cell transplant and chemotherapy; as of 2017, he has been in remission. In response to this case, Virginia passed state legislature known as Abraham's Law in February 2007 (Ross 2009). This law allows teenagers 14 years of age and older with a life-threatening condition and their parents to refuse medical treatments or choose alternative treatments as long as the teen seems to be mature, all the possible treatment options have been considered by the teen and their parent, and the choice is in the teen's best interest.

The way Abraham's case played out was shocking; the fact that he was able to utilize a publicly condemned medical treatment, one that had specifically been blacklisted by the FDA years prior seemed like a questionable decision. This is obviously a

nonefficacious medical treatment, which is what court typically supports in these cases (Caplan 2007). However, what I want to discuss in regards to Abraham's case is the law that passed in response to it; as we discussed earlier, this is how the mature minor doctrine becomes a statute. We can see, though, from the wording of the law, how vague these laws tend to be. On the one hand, I appreciate the protections put in place by creating a law such as this; data has shown that adolescents and young adults with life-threatening illnesses such as cancer want to be actively engaged in the decision-making about their care, and this law allows that (Marron and Meyer 2021). Obviously, Abraham's Law falls into similar pitfalls that other mature minor doctrine statutes do in that there is no established standard for what is defined as mature, which allows that determination to be rooted in subjectivity. It also is written as if it requires a parent to agree with the child's decision; this is problematic as a "2020 analysis demonstrated that adolescents have strong end of life perspectives, which are typically incongruent with what parents believe it to be" (Marron and Meyer 2020, 344). Even with all these flaws, this law is truly groundbreaking because it explicitly gives minors the right to refuse medical treatment in cases of life-threatening illness, setting a standard that should be adopted by other mature minor doctrine statutes.

The second case I want to examine, that of Dennis Lindberg, is truly different from any other case I came across in researching the mature minor doctrine. Dennis was a 14 when he was diagnosed with acute lymphoblastic leukemia in early November 2007. Dennis was under the custody of his aunt, who he had lived with in Seattle, Washington for several years after his parents were imprisoned. While living with his aunt, he became a devout Jehovah's witness; it is common knowledge that Jehovah's witnesses believe

that accepting blood transfusions violates God's will. It was under this edict that Dennis, with the support of his aunt, refused a blood transfusion, which would have statistically increased his chances of living by 75% as it would have allowed him to be healthy and stable enough to start chemotherapy (Raftery 2018). However, what makes this case so profound is that both the doctors at Seattle Children's and the lawyers consulted outright agreed that Dennis could refuse the transfusion, even though it could mean that he would die. "Doctors must respect young teens' medical decisions only if they are mature enough to understand the consequences", and discussions with Dennis demonstrated that he understood what would happen if he did not receive the transfusion (Raftery 2018). A meeting was held between social work and five senior oncologists to discuss case and they unanimously agreed that Dennis had the right to die because he was able to clearly express his position; if a 14-year-old can do that, then they deserved to have that position respected. At the same time, Dennis's biological parents learned of what was happening and made an appeal to the State Department of Social and Health Services to make Dennis receive the transfusion. As one doctor said when he testified, Dennis would accept the initial blood transfusion because his condition was so poor that he would not be strong enough to fight them off. But as his anemia resolved, he would start fighting them, which would require them to sedate and restrain so that they could continue to force the transfusion upon him; that is not something they want to do to somebody who so eloquently explained what receiving a transfusion would do to him (Raftery 2018). The judge ended up denying the unconsented blood transfusion; Dennis died 7 hours later.

The nature of this case is extraordinary; the first thing that I found striking about this case was that Dennis' refusal of care was originally supported by all parties involved. It was only due to his biological parents' involvement that the case ended up in front of a judge; all of the doctors, both those providing care and those consulted, as well as the lawyers agreed that Dennis had jurisdiction in refusing the blood transfusion. This is likely due to the standard has already been established for Jehovah Witnesses. "The courts recognized the First Amendment right of individuals whose refusal of medical treatment was based on their religious beliefs in 1965 with the Illinois Supreme Court case that ruled in favor of an adult Jehovah's Witness, stating they had a First Amendment right to exercise religion freely in the context of refusing a blood transfusion" (Driggs 2001, 692). Dennis was deemed to be mature because he was able to clearly state his reasoning behind why he was refusing the blood transfusion; this gave him the right to make decisions based on his judgment about what was in his best interest (Ross 2009). He was empowered to make healthcare decisions because he knew what he wanted to happen to his body and what his future would be in making that decision, demonstrating an emotional maturity that we tend to expect to come with the transition to adulthood (Weithorn 2020). Yet, nothing magical happens when someone turns 18 and officially becomes an adult to impart them with new capacity for making independent medical decisions (Marron and Meyer 2021). As we see with Dennis' case, this idea that minors are only ruled by their emotions and therefore incapable of making sound judgments about medical decisions is blatantly untrue. However, what truly sets this case apart from the other cases discussed in this paper is that Dennis' choice to refuse care resulted in his death, which both the medical and court systems hope to avoid when

issues of refusing care are brought forward. Survival has been a driving factor for both prolonging and mandating treatments in patients with life-threatening or life-limiting illnesses (Gorgos and Ghosh 2019). This focus on survival is because of our decidedly-death denying culture, which together with the grief associated with the loss of a child, creates the ethical dilemma that comes with end-of-life care for children (Sellers and Rasmussen 2019). However, the patient's quality of life must also be considered, and not that which the physician envisions it to be, but that which is perceived by the patient and their family (Gorgos and Ghosh 2019). We typically only consider the physical factors when considering a patient's quality of life, but it is important to consider their social, psychological, and spiritual wellbeing as well (Gorgos and Ghosh 2019). As Dennis' aunt said, "I knew that I was helping him to actually die. But the other option was more horrifying. To abandon Dennis in his strong conviction to uphold Bible principles as we understand them and allow transfusions to be forced upon him, would have killed him in so many other ways" (Raftery 2018). For Dennis, bodily autonomy in light of his acute lymphoblastic leukemia diagnosis meant respecting his religious beliefs, even at the cost of his own life. It is "...the possibility of future cases like that of Dennis Lindberg that underscores the importance of examining when the competence of minors to make treatment decisions matter in the law"; not every minor has the capacity to make such a decision, but every minor deserves to be heard because "the competence of a teen does not change according to their prognosis" (Weithorn 2020, 26; Duncan and Sawyer 2010, 113).

## CHAPTER 5: WHERE DO WE GO FROM HERE?

The mature minor doctrine creates the possibility for minors that take a more active role in their health care, something that is especially desired for adolescents who have life-threatening illness. The way in which the mature minor doctrine exists in the United States, though, leaves much to be desired. Most states do not even have the mature minor doctrine as a law, and those that do, have kept the wording of it vague so that the determination of whether the minor is mature enough to have capacity to provide full consent is left to the whims of the court system. The lack of standards as to what a mature minor is, how their capacity to consent is determined, and in what settings they can exercise this right is another major stumbling point. As a society, we often get caught up on the idea that adolescents are unable to make wise choices; that they are impulsive, risk takers who are ruled by their emotions and the inclinations of their friends. Yet, as we have seen from the both the cases we discussed as well as the research done into this topic, we underestimate adolescents' potential to know what is right for themselves in addition to their ability to reflect on the long-term consequences of their actions as it relates to their health. Some adolescents may not be ready to make these decisions, but there are others that are; who are we to prevent them from having the right to their own bodies? In addition to that, this concept of decision-making capacity is fruitless because its assessment by the judicial system is very different from that of the medical system; one standard needs to be established and implemented. And while several states have the mature minor doctrine, it only explicitly gives minors the rights to consent to treatment; this is not the issue when it comes the mature minor doctrine as we have seen with the cases of Cassandra, Abraham, and Dennis. Surveys have shown that pediatricians are

more likely to support a minor if they are making the “right choice”, one that aligns with what the doctor sees as in their best interest, meaning they choose treatment (Duncan and Sawyer 2010). Pediatricians, on the other hand, are less likely to respect minors’ decisions in life-threatening conditions; these are the moments in which pediatricians need to take a step back because our perceived notion of quality of life and best interest may not reflect those of our patient (Talati and Lang 2010). While the mature minor doctrine is now well enshrined in our thinking about adolescent development, I believe its controversial nature is what has kept us from expanding it from its current, ill-defined form.

So where can we go from here? I have several suggestions that I believe would be crucial in moving the mature minor doctrine in the direction of progress for minors, their families, the medical system, and the legal system. The first suggestion is every state needs to have a mature minor doctrine statute; there have been enough cases across the country that have demonstrated that there is a need for this law. The first case that I came across regarding the mature minor doctrine as it pertained to refusal of treatment in the setting of life-threatening illness was in 1994, and rather than slowing down, there has only been an increase in the number of these cases. The second suggestion that I have is to establish a standard for the mature minor doctrine; this should cover how a mature minor is defined and what characteristics they need to have to demonstrate that they have decision-making capacity. One suggestion is to “institute a bright-line, allowing minors to make their own medical decisions starting at a certain age, such as 16. A rule such as this would not require a health care provider, or the legal system, to become involved in the decisions of minors near the age of majority” (Slonina 2007, 208). Another proposed

suggestion is to “[determine] decision-making capacity in pediatrics by adopting institutional guidelines and giving practical recommendations designed in collaboration with legal and ethical consultants; this will create an awareness for conceptual issues and provide guidance in the more challenging situations”, such as refusing care in life-threatening illness or discordance between the parent and child (Ruhe et al 2014, 780). Finally, the mature minor doctrine needs to allow for refusals of care; we cannot only grant adolescents the right to the bodies when we agree with their decision. The third suggestion that I have relates to how the judicial system works with physicians to determine the maturity of a minor. “Incorporating judicial deference to a physician’s determinations of a child’s maturity in mature minor cases will allow the common law to begin to see the development of a defined standard for the mature minor doctrine based on scientific research and empirical data instead of relying on the perceptions of judges, which are typically based on personal experience and brief impressions of the minor” (Slonina 2007, 213). The onus should be with the pediatrician to make this call because they have the best understanding of the development of adolescents’ capacity, and therefore, decision-making power. Making these changes will allow us to be able to better navigate mature minors and treatment refusals, decreasing the need for court involvement, which damages the clinician-patient-parent relationship (Marron and Meyer 2021). To bring this to a close, the mature minor doctrine has so much possibility; it is time to start giving weight to children’s preferences when it comes to life-sustaining treatment and reform of the mature doctrine can do this.

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