

"Do No Harm": An Evaluation of the Courts' Decision-Making Policies in Overruling Children & Families' Refusal of Treatment

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Abstract: *The purpose of this research paper is to prove why the courts have the authority to overrule families' and children's refusal of potentially life-saving treatment. The author describes the decision-making policies and laws used to guide judges' decisions and justify their rulings. The case of Cassandra C., a seventeen-year-old minor diagnosed with Hodgkin's lymphoma, helps demonstrate how these policies are practiced in the courtroom. Court cases, particularly the case of Daniel Hauser, are used as evidence to describe why the court's actions are warranted even in cases in which treatment is refused based on a family's religious values. The courts' decisions are ultimately justified since legislation's primary initiative is to protect the greater welfare of society. After proving that the courts' decisions are warranted, the author suggests that legislatures adopt the harm principle, contrary to the best interest standard, to not only justify court intervention, but also to clarify the circumstances necessary for involvement. With support from professionals in this field of study, the author also encourages legislators to implement the constrained parental autonomy model as opposed to the mature minor doctrine. By employing the harm principle and constrained parental autonomy model, the author argues that these decision-making laws will clarify when court intervention is justified, and thus cause less conflict in the courtroom.*

In January of 2015, the Connecticut Supreme Court ruled seventeen-year-old Cassandra C. too immature to justifiably refuse chemotherapy treatment after being diagnosed with Hodgkin's lymphoma (Harris, 2015). Despite her physicians' persuasive evidence proving the treatment's potential for success, Cassandra and her mother, Ms. Fortin, argued to court officials that chemotherapy was simply "poison" and had the capacity to "kill everything else" in the human body (Harris, 2015). Legally, the court could not permit Cassandra to refuse

treatment based upon her fear of its potential side effects. Because no sufficient alternative care other than chemotherapy could guarantee an “85 percent chance of being disease free in five years,” Cassandra and her mother’s refusal could not be deemed medically acceptable (Harris, 2015). Other patients and parents, like Cassandra and her mother, who have attempted to refuse life-saving treatment, argue that forcing medical care upon a child and acting against a parent’s wishes to reject conventional care violate basic human rights. Court officials, however, have the authority to supersede patients’ and parents’ decisions to refuse potentially life-saving treatment to protect the greater welfare of society. Although federal and state laws permit the courts to override parents’ refusal, legislators must adopt the *harm principle* instead of the *best interest standard*, and the *constrained parental autonomy* model instead of the *mature minor doctrine*, into law to better guide judges’ decisions in the courtroom.

Determining whether a patient and their family’s refusal of treatment are justifiable can be an arduous process, depending on the circumstances of the case. Beginning in the 1800s, the Supreme Court noted that “[no] right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession, and control of his own person, free from all restraint or interference of others” (as cited in Foederer, 2007, p. 108). To avoid a charge of battery, “the common law doctrine of informed consent was established, requiring any person about to perform a medical procedure on another to receive prior consent” (Foederer, p. 108). Based on these historical doctrines, physicians are not permitted to force treatment on a patient without permission from either the patient themselves or their parents in cases involving children. The Supreme Court has recognized that “parents possess the requisite knowledge and experience to make decisions for their children,” since minors typically cannot be considered competent to make legally binding health decisions on their own (O’Connor, 2009, p. 63). However, when physicians’ recommendations and solutions to treating a child’s life-threatening illness are unsatisfactory to the family, the case can be overturned

by court officials who possess the right to evaluate whether or not intervention may be necessary. Though parents do hold some autonomy over children's medical decisions, the courts must adhere to a variety of decision-making guidelines to ensure children's safety.

Comparing the Courts' Decision-Making Guidelines

Two common decision-making guidelines the courts employ in cases involving parents' and minors' refusal of efficacious treatment are the *best interest standard* and the *harm principle*. According to Thomas L. Beauchamp and James F. Childress (2001), the best interest standard is defined as one in which "a surrogate decision maker must determine the highest net benefit among the available options, assigning different weights to interests the patient has in each option and discounting or subtracting inherent risks or costs" (p. 102). In other words, this guideline compares treatment options in order to ensure that parents' decisions meet a child's needs. The way this policy is interpreted varies state by state; in New York "a preponderance of evidence is required" in order for treatment to be in the best interests of a patient in comparison to Texas, which requires a "stricter standard of clear and convincing evidence" (Foederer, p. 112). Because the best interest standard is a subjective measure, the courts may employ the harm principle as a more definitive guideline for assessing whether or not parents' refusal of potentially life-saving treatment is justified. In defining the harm principle, the Supreme Court rules that the "only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant" (as cited in Holtug, 2002, p. 357). Contrary to the best interest standard, the harm principle permits the court to act when a child's life is substantially threatened. Nevertheless, the best interest standard and the harm principle both serve to protect children's welfare.

Though the courts utilize these guidelines synonymously, the best interest standard is a value-based guideline whereas the harm principle identifies a threshold for which parents' de-

cisions are considered unacceptable. The best interest standard essentially involves “assessments of which values should carry the most weight,” which as a result, “pits the state’s determination of the ‘best interest’ against that of the parents” (Diekema, p. 247). The harm principle, on the other hand, takes a different approach in that it “justifies interference” not because a parent’s decision is “contrary to the child’s best interest, but rather that the decision poses some harm to the child” (Diekema, p. 250). The best interest standard therefore is best suited for objective medical situations in which the treatment’s benefits cannot be challenged by the parents’ concerns for its potential side effects or inherent risks. This standard takes many medical considerations into account compared to the harm principle, which only addresses the primary concern: the level of harm the patient endures.

Once parental autonomy has been considered, certain state courts may enact the *mature minor doctrine* to not only promote minors’ abilities to make their own medical decisions, but also to protect the welfare of all children in the event that parents’ decisions can be deemed ethically questionable. The “mature minor” doctrine, which allows under aged children “to give consent to medical procedures if they can show they are mature enough to make a decision,” has been employed by some states to promote child autonomy (“The Mature Minor Doctrine,” n.d.). Since the mature minor doctrine was established in 2002 and is considered a relatively “new legal concept,” only Nevada, Arkansas, “Pennsylvania, Tennessee, Illinois, Maine and Massachusetts...have adopted the doctrine as law” (“The Mature Minor Doctrine,” n.d.). Because the Supreme Court has never defined the doctrine’s applicability to medical procedures, states have interpreted it differently. Illinois, for example, allows a mature minor to refuse medical care only if the decision does not threaten the child’s health (O’Connor, p. 63). Virginia, on the other hand, “permits a minor 14 years or older to refuse, with parental acquiescence, medical treatment, even when the minor suffers from a life threatening disease” (O’Connor, p. 64). A child who is only five years old would not be considered mature; however, the doctrine may be applicable

in a case involving an individual who has reached adolescence and can comprehend the consequences of refusing treatment. Court officials, as a result, are responsible for assessing a child's ability to make a rational medical decision based on their specific observations and analyses conducted in the courtroom.

Though the courts have used this doctrine as a primary guideline in cases involving children, some scholars have argued for an alternative measure; Lainie Freedman Ross, a professor of medicine and "chair of the American Academy of Pediatrics" at the University of Chicago, ("Lainie Freedman Ross," n.d.) has suggested that the courts' adopt a guideline she terms the "constrained parental autonomy model" (Ross, 2009, p. 310). This decision-making standard "presumes that parents should have the authority to make life-saving decisions for their children," but suggests that parental autonomy "is not absolute" and is "constrained by the respect that is owed to the child" (Ross, p. 310). Much like the mature minor doctrine, this guideline honors children's decision-making capabilities; however, Ross' model suggests that parental autonomy be valued first and foremost. The most important component of this model relates to "positive conception," which "requires that parents help their child develop the skills to become an independent and autonomous decision-maker when he attains adulthood" (Ross, p. 310). Ross argues that parents should help their children adopt better decision-making skills when assessing whether or not treatment is desirable or necessary. This model differs from the mature minor doctrine in that it does not abandon children in making a medical decision on their own, but rather addresses "the right and responsibility of parents to promote their adolescent's long-term autonomy" (Ross, p. 311). Despite these guidelines' inherent differences, they both attempt to protect adolescent autonomy.

A court's primary initiative in employing these decision-making guidelines is to preserve a child's life, which often means enforcing conventional treatment despite patients' and parents' objections. Cases often become controversial when the court must face not one, but two opposing forces: both the child and the parent. In the case of Cassandra C., for example, both

she and her mother refused chemotherapy because of their concerns for its potential side effects. Though Cassandra should have been evaluated under the mature minor doctrine because of her age, her attorneys failed “to prove her status as a mature minor in the initial trial” (Thielking, 2015). As a legally deemed “immature minor,” the court decided that while undergoing treatment would be in Cassandra’s best interest, it was also necessary to remove her from her mother’s care since she had neglected to bring Cassandra to some of her appointments and failed to tend to her daily medical needs on a timely basis (Harris, 2015). According to Suzanne E. Collins, the “Director of the American Association of Nurse Attorneys” and nursing professor at the University of Tampa, the best interests of the child are always “to live because the absence of life is not the best interest no matter what the life is” (personal communication, April 8, 2016). Whether Cassandra was aware of the consequences of her actions at seventeen-years-old, the court’s decision to enforce conventional treatment ultimately served to protect her life, given her significantly low odds of survival without medical care.

Case Study: Refuting Arguments Against Court Intervention

Even though the court has the authority to override patients’ and parents’ decisions to refuse potentially life-saving treatment, in some instances parents contend that they legally possess the freedom to reject conventional medicines that do not coincide with their family’s religious beliefs. Religious arguments to refuse medical care are not irrational; in fact, the First Amendment, “one of the most cherished of all our constitutionally guaranteed liberties,” grants citizens the right to express their spiritual beliefs (Lee, 2005, p. 71). In the *Cantwell et al. v. Connecticut Supreme Court* case, Justice Owen Roberts claimed that the First Amendment “embraces two concepts—freedom to believe and freedom to act” (as cited in Lee, p. 71). Faith not only affirms a person’s beliefs, but also naturally guides an individual’s actions. The courts are thus forced to answer a difficult question: Should parents and children refusing life-saving treatment prevail in the courtroom because of

their constitutional right to express their religious values? Some parents, such as the parents of Daniel Hauser, a 13-year-old boy who refused treatment after being diagnosed with Hodgkin's Lymphoma in 2009, have argued that religious freedom supersedes the court's authority to enforce potentially beneficial treatment. Daniel and his parents rejected chemotherapy and insisted on using only "natural" remedies for treating his cancer as members of the Nemenhah religion, which upholds a spiritual journey from sickness to health (Novella, 2012, p. 138). Even though the judge ruled that "the state's interest in protecting the child overrides the constitutional right to freedom of religious expression," the parents' attorney, Calvin Johnson, asserted that "every one should be able to get medical care in line with their conscience" (as cited in Associated Press, 2009). Daniel's parents further contended that officials did not have the right to go "against the spiritual law to invade the consciousness of another person without their permission" (Associated Press, 2009). Daniel's parents' religious argument against conventional treatment could be well supported by one of the most influential and widely enforced amendments in the U.S. Constitution. However, the court's interests in protecting the child were more important than honoring the family's religious freedom. Though court officials were criticized for infringing on Daniel's basic religious rights, they intervened to keep Daniel out of harm. The court's ruling ultimately saved his life and perhaps rescued him from making a decision he did not intend while under the influence of his parents' religious values.

Although the First Amendment protects citizens' religious freedom, courts' decisions to overrule a family's refusal of treatment are justified since religious views often overshadow a child's vulnerability and the severity of their illness, and thus place the child in harm. District Judge John Rodenberg ruled that Daniel only had a "rudimentary understanding at best of the risks and benefits of chemotherapy" and did not believe he was currently ill when he was, in fact, very sick (as cited in Associated Press, 2009). His mother, Colleen Hauser, also testified in court that her son "was not in any medical danger at this point," signifying the parents' current state of denial (as cited

in Associated Press, 2009). Because both Daniel and his parents doubted the seriousness of his illness, intervention was necessary to protect his life. Even with a “ninety percent chance of being cured with chemotherapy and radiation” and a five percent chance of survival without it, both Daniel and his parents still refused (Associated Press, 2009). In fact, reports indicate that Daniel’s cancer responded well to chemotherapy even though it made him “sick, dizzy, and tired” (Forliti, 2009). According to Dr. Collins, medical treatment refusal cases that involve a religious system, like this one, can “easily become criminal cases” (personal communication, April 8, 2016).

In fact, many cases involving the refusal of efficacious medical treatment have resulted in criminal charges, as demonstrated by the case of Ian Lundman, an eleven-year-old child who died from juvenile onset diabetes. Because Ian’s parents were Christian Scientists and did not believe in using conventional treatment, they refused all medical care on his behalf. Under the Christian Science Church, if a parent is concerned about their child’s health “a journal-listed Christian Science practitioner can be contacted” instead (Lee, p. 66). His mother, Kathleen McKown, reached out to Mario Tosto, a journal-listed specialist, and “hired him to pray for Ian” (Lee, p. 66). Ian’s condition, however, only continued to worsen. Since the young boy died from not receiving the insulin he needed shortly after the onset of his symptoms, the parents “were charged with second-degree criminal manslaughter” (Lee, p. 66). The “district court, however, dismissed the indictments, a decision affirmed by the Court of Appeals of Minnesota and the Minnesota Supreme Court” (Lee, p. 67). The parents were excused from this crime in accordance with the Minnesota child neglect law which “specifies that if the person responsible for the child’s care ‘in good faith selects and depends upon spiritual means or prayer for treatment or care of disease or remedial care of child, this treatment shall constitute health care’” (as cited in Lee, p. 67). This case, though it occurred in the late 1980s, goes to further prove how parents’ religious values can conceal the severity of a child’s illness; without court intervention, Daniel’s family may have faced the same tragedy Ian’s parents experienced. Though they

were excused for their actions because of Minnesota's rather lenient child abuse law, the case illustrates why the court's decisions to overrule parents' refusal of treatment are justified.

Court intervention is therefore required when parents place their children in harm by replacing medically recommended, conventional methods with other non-scientifically proven medicine practices. Both advocates of complementary and alternative medicine (CAM), who believe in the effectiveness of natural remedies (supplements, vitamins, and ionized water), and advocates of religions whose faith conflicts with modern medicine, preach "health care freedom" (Novella, p. 140). While health care freedom may be a valued liberty to religious followers in American society, legislators are often skeptical when patients and families decide to withdraw from conventional treatment to undergo natural medicine practices, and then claim that the treatment conflicts with their religious values, simply to better justify their refusal. Steven Novella, a neurologist and professor at Yale University School of Medicine, explains "that while there are those who are sincere in their Nemenhah beliefs, others have exploited the religion to simply sell supplements or practice medicine under the cover of religion, using the 'Native American' angle as a selling point" (Novella, p. 140). Because diet treatments, energy therapies, and other natural remedies have not been proven to have substantial curing effects on terminally ill patients, religion serves as a buffer for employing such methods. Novella adds, "Once regulators get a whiff of religious issues in a case they immediately back off and become reluctant to get involved. Some CAM proponents have therefore exploited this as a mechanism to shield themselves from scrutiny and regulation" (p. 140). Whether CAM proponents intentionally use religion as a selling point, such remedies still neither replace nor serve as justification for refusing conventional treatment because they have not been proven to cure illnesses, necessitating the need for court involvement.

Parents who refuse treatment on their child's behalf also argue that the courts infringe on their right to make medical decisions in the best interests of their child, a freedom clearly granted by law. In support of Daniel's parents and their autonomy in

the decision, Philip Elbert, Daniel's court-appointed attorney, claimed that he felt the judge's overruling was "a blow to families" (as cited in Novella, p. 141). In a general statement, Elbert further contended that the court "marginalizes the decisions that parents face every day in regard to their children's medical care" and that the court's decision to force Daniel into treatment only affirmed "the role that the big government is better at making decisions for us" (as cited in Novella, p. 141). Though the court infringed on the parents' autonomy in the decision, the state recognized their refusal as a genuine attempt to protect Daniel; the court neither accused the parents of child neglect nor forced Daniel to leave his home. In fact, the court's involvement was only necessary to protect Daniel's health. According to Novella, parents are given "significant leeway in making medical decisions for their children and only the most extreme cases are brought before the courts, and even then the parents are given primary consideration" (Novella, p. 142). The court's main objective was to preserve Daniel's life, not to devalue his parents' decision or challenge their autonomy.

While the courts have the authority to overrule patients' and families' decisions to refuse potentially life-saving treatment in order to protect children's welfare, some of the laws and policies that guide these rulings are not defined or clarified appropriately, thus stimulating controversy in the courtroom. In a Texas court hearing, the parents of Sydney Miller argued that doctors treated their premature daughter without proper consent; they had signed legal documents indicating that they did not want medical treatment if she was born with a terminal illness. According to Texas state law, parents could "withdraw life sustaining medical treatment from a child" only if they had a terminal condition (Woods, 2003). The law granting the parent's right to refuse, in this case, did not supersede the Texas law outlining when they could withhold treatment; the court ordered that the Millers had no right to deny medical aid, even though their daughter was nearly blind and severely retarded (Woods, 2003). In other words, the parents did not have the authority to negate treatment and end a potentially healthy and sustainable life just because their daughter was disabled. In this case the

courts employed the best interest standard in asserting that the parents' refusal did not benefit Sydney. However, in the parents' defense, the state laws failed to define what circumstances prevented them from refusing treatment, why the physicians' actions were justifiable, and how those actions served the best interests of the child. Had the laws been clearly defined and applied, the court may have avoided this misunderstanding.

Changing the Law: Evaluating the Courts' Decision-Making Guidelines

In making decisions to promote the safety and well-being of a child, the courts often use the best interest standard as a guideline for assessing whether or not treatment fulfills the child's needs; although this standard has succeeded in preserving children's lives as demonstrated in the case of Cassandra C., Daniel Hauser, and Sydney Miller, it is an exceedingly complex principle to define. According to Attorney Erica K. Salter (2012), the best interest standard fails to clarify the "terms of (1) what it requires, (2) of whom it requires anything," and "(3) when (or in what context) it requires those things" (p. 195). Because the best interest standard fails to define any of these conditions, the guideline is regarded as ineffective. Some parents, for instance, when left to decide whether treatment is in the best interests of their child, "may place greater weight on the risks, side effects, discomforts, and disruptions that the child may endure in being treated, perhaps making the judgment that the increased chance of survival does not justify those burdens" (Diekema, p. 247). In other words, the court's interpretation of what is in the best interests of a child medically may conflict with the parents' views of the treatment's value, and the parents' objections to conventional care may stem from their concerns or fears over the treatment process their child must undergo. Court officials, on the other hand, focus on the outcome of refusing potentially life-saving treatment and the stark realities children will face if parents do not adhere to their basic needs. According to Douglas Diekema, a pediatrics professor at the University of Washington, the best interest standard is also flawed because "there are few situations in which society actually requires parents to

always act in a way that is optimal to their children. In seeking to optimize family welfare, parental decisions may commonly subjugate the interests of individual children" (Diekema, p. 247). The court can surely intervene, but their involvement cannot be fairly justified since parents' desires to fulfill the best interests of their family often supersede the best interests of the individual child. Salter adds that an "appeal to a child's best interest is unfeasibly demanding" no matter how "widely one decides to cast the net of interests when determining the best interest of a child" (p. 194). Though parents' decisions may be unjustified because their refusal is based on familial interests as Diekema suggests, the standard is indefinable regardless of the wide scope of interests taken into consideration. Since this standard is indeed value-based, it does not serve as a proper guideline.

Rather than practicing the best interest standard, the courts can better justify their intervention in any given case by employing the harm principle as a primary guideline. Although the best interest is a value-based standard, the biggest problem with it is that it "represents the wrong standard. State intervention is not justified because a decision is contrary to the child's best interest, but because it places the child at significant risk of serious harm" (Diekema, p. 253). Since state action in many cases of medical neglect has been defined as the failure to "provide the minimum quality of care which the community will tolerate," this seems to be pointing towards a harm principle rather than a best interest standard (Diekema, p. 249). In protecting children's welfare, the court holds the responsibility to ensure that an immature minor is safe; therefore, this includes enforcing treatment in instances in which a child can be considered neglected without receiving such care. Furthermore, "the American Academy of Pediatrics Committee on Bioethics argues that state intervention should be a last resort wielded only when treatment is likely to prevent substantial harm or suffering or death" (as cited in Diekema, pp. 251-252). Given this requirement for intervention, under the harm principle the court's actions are inherently justified when families and patients refuse treatment that is more beneficial than harmful.

Though the harm principle itself does not quantify the level of harm that must be induced, it serves its intended purpose in guiding the courts' decisions more suitably in regards to a child's health when compared to the best interest standard.

The best interest standard is not the only principle that is flawed in its representation; the mature minor doctrine also fails to serve its intended purpose in honoring children's autonomy. The doctrine's ambiguity is evident in cases in which the "courts may argue that their decisions are based on 'mature minor' statutes...yet it is not clear that the courts would uphold the refusal if the parents did not agree with the teenager as in the case of minor refusal. This suggests that the 'mature minor' doctrine is only invoked when the parents concur, which makes one question whether the courts' decisions are truly being based on respect for adolescent autonomy" (Ross, p. 308). The doctrine essentially is only applicable when the parents agree with the child; since its application is typically only viable in this particular circumstance, the doctrine neither promotes parental guidance in the decision-making process nor honors children's potential decision-making capabilities.

Even though the mature minor doctrine is flawed in its application, the real problem is that it grants children sole decision-making responsibility in life-threatening situations simply based on the maturity a child displays in the courtroom. Although "young children have a keen awareness of their own clinical situations and options and should be involved as best as is possible in decision making," children are not expected to be competent and experienced enough to refuse treatment on their own (Fleischman & Collogan, 2004, p. 745). This does not mean that children should be uninvolved in the decision, since refusing treatment directly impacts their life only, but rather parents should serve as guides to help their children in making rational health decisions.

To improve the application of the mature minor doctrine in cases involving life-threatening illness, the courts should apply Ross' constrained parental autonomy model, which not only further defines the harm principle, but also promotes children's long-term decision-making skills and emphasizes the impor-

tance of parental guidance. In support of this model Diekema argues that it “allows parents to trade the best interests of one child for familial interests as long as the basic needs of each child in the family are secured” (p. 251). Unlike the best interest standard, which does not justify parents’ decisions based on the best interests of the family rather than on the individual child, this model allows parents to make such decisions, granted that no child is subject to “abuse, neglect, or harm” (Diekema, p. 251). This model thus coincides with the harm principle by further defining and quantifying what constitutes as harmful. The model also fulfills the mature minor doctrine’s intended purpose in promoting the “goods, skills, liberties, and opportunities necessary” for children “to become autonomous adults capable of devising and implementing their own life plans” (Diekema, p. 251). Rather than giving a child complete responsibility in regards to their health, this model suggests that promoting children’s long-term autonomy is most important since “adolescent maturity is necessary but not sufficient to justify sole decision-making authority in cases where effective life-saving therapies exist” (Ross, p. 311). The model accounts for children’s lack of experience and maturity, but also promotes their autonomy in that they are involved in the process and learn decision-making skills for the future.

Although the legislation that is in place is a “pretty good framework,” the decision-making guidelines need to be better defined and applied in law (S. E. Collins, personal communication, April 8, 2016). Cases really become muddied when certain “factors come into play: the belief values of the judge, the values of the family,” and “interveners like various churches” (S. E. Collins, personal communication, April 8, 2016). By replacing the best interest standard for a more definite guideline, the harm principle, and adopting the constrained parental autonomy model—a more suitable guideline for addressing children’s decision-making abilities than the mature minor doctrine—legislators can better guide judges’ decisions and therefore mitigate confusion or conflict in the courtroom. Courts’ abilities to supersede patients’ and families’ decisions to refuse potentially life-saving treatment will thus become less controversial. Even

"Do No HARM"

though religious arguments are persuasive and judges' interpretations of these laws may vary, the courts have the ultimate authority to overrule children's and families' refusal of potentially life-saving treatment to best protect the health of society.

Note: This essay was composed in Dr. David Reamer's AWR 201 class.

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