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PARENTAL REFUSALS OF MEDICAL TREATMENT: THE HARM PRINCIPLE AS THRESHOLD FOR STATE INTERVENTION

ABSTRACT. Minors are generally considered incompetent to provide legally binding decisions regarding their health care, and parents or guardians are empowered to make those decisions on their behalf. Parental authority is not absolute, however, and when a parent acts contrary to the best interests of a child, the state may intervene. The best interests standard is the threshold most frequently employed in challenging a parent's refusal to provide consent for a child's medical care. In this paper, I will argue that the best interest standard provides insufficient guidance for decision-making regarding children and does not reflect the actual standard used by medical providers and courts. Rather, I will suggest that the Harm Principle provides a more appropriate threshold for state intervention than the Best Interest standard. Finally, I will suggest a series of criteria that can be used in deciding whether the state should intervene in a parent's decision to refuse medical care on behalf of a child.

KEY WORDS: best interest, children, harm principle, informed consent for minors, medical neglect, parental refusals, proxy consent, surrogate decision-making

INTRODUCTION

It is well established in American law that a patient must give informed consent before a physician may administer treatment. The U.S. Supreme Court recognized the right to refuse unwanted medical treatment as early as 1891 in Union Pacific Railway Company v. Botsford: "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."[1] The Supreme Court has reaffirmed this notion on several occasions, most recently in Cruzan v. Director, Missouri Department of Health: "a competent person has a constitutionally protected liberty interest in refusing unwanted medical treatment."[2] The failure to obtain informed consent constitutes a battery under the law, for which a physician might be either

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criminally or civilly liable. This right to refuse treatment and grant informed consent does not disappear for individuals who are incompetent. Rather the right is one that must be exercised for them.[3]

Under U.S. law, minors are generally considered incompetent to provide legally binding consent regarding their health care, parents or guardians are generally empowered to make those decisions on their behalf, and the law has respected those decisions except where they place the child's health, well-being, or life in jeopardy.[4] There are several good reasons for this presumption to respect parental autonomy and family privacy.[5] First, because most parents care about their children, they will usually be better situated than others to understand the unique needs of their children, desire what's best for their children, and make decisions that are beneficial to their children. Second, the interests of family members may sometimes conflict, and some family members may be subject to harms as a consequence of certain decisions. Parents are often better situated than others outside of the family to weigh the competing interests of family members in making a final decision. Third, parents should be permitted to raise their children according to their own chosen standards and values and to transmit those to their children. Finally, in order for family relationships to flourish, the family must have sufficient space and freedom from intrusion by others. Without some decision-making autonomy, families would not flourish, and the important function served by families in society would suffer.[6, 7] For all of these reasons, U.S. law (and most ethical analysis) begins with the assumption that parents are the persons best suited and most inclined to act in the best interests of their children,[8] and that in most cases they will do so.[9] In most situations, parents are given wide latitude in terms of the decisions they make on behalf of their children.[10]

Parental authority is not absolute, however, and when a parent[11] acts contrary to the best interest of a child, the state may intervene.[12] The doctrine of *parens patriae* holds that the state may act as "surrogate parent" when necessary to protect the life and health of those who cannot take care of themselves, including children.[13, 14] According to the Supreme Court in Prince v. Massachusetts, ". . .neither rights of religion nor rights of parenthood are beyond limitation. Acting to guard the general interest in youth's well being, the state as *parens patriae* may restrict the parent's control by requiring school attendance, regulating or prohibiting the child's labor, and in many other ways."[15] Child abuse laws are recognition that parental rights are not absolute. If a parent refuses to provide necessary care to a child, the state can assume temporary custody for the purpose of authorizing medical care under the claim of medical neglect.[16] The "best interest" standard has become the judicial and ethical standard used to determine when state interference is justified.[17] In the remainder of this paper, I will argue that the best interest standard provides insufficient guidance for decision-making regarding children and does not reflect the actual standard used by medical providers and courts. Rather, I will suggest that the "harm principle" provides a more appropriate threshold for state intervention than the "best interest" standard. Finally, I will suggest a series of criteria that can be used in deciding whether the state should intervene in a parent's decision to refuse medical care on behalf of a child.

THRESHOLD FOR INTERVENTION: BEST INTERESTS

Several judicial standards have evolved in an effort to determine the proper course of action for individuals who are judged incompetent to make medical decisions for themselves. In general, a proxy decision-maker is to make decisions that most faithfully reflect the patient's wishes or, if those wishes cannot be known, the best interest of the patient.[18] For formerly competent individuals, a subjective or pure autonomy standard is commonly applied. A subjective standard attempts to rely on the expressed wishes of formerly competent individuals in making medical decisions on their behalf. In order to be useful, this standard requires that the individual was competent to make decisions in the past and that she expressed sufficiently specific preferences regarding future medical care that surrogate decision-makers can apply those preferences as they make decisions that ideally resemble those she would have made for herself. The more questionable substituted judgment standard rests on the value of self-determination, but attempts to apply it to persons who have never been competent. It requires the surrogate decision-maker to "don the mental mantle of the incompetent"[19] in an effort to determine what the incompetent person would have wanted regarding the proposed treatment if he or she were capable of making a decision.[20] Neither of these standards can be reasonably applied to young children, individuals who have never been competent or given thought to what they would want in a difficult medical situation. A standard rooted in self-determination must be replaced with one based on the protection of patient welfare.[21] The concept of "best interests" has been employed in family law regarding decisions concerning adoption, foster care, and custody after divorce. It has also become the prevailing standard used to judge the adequacy of medical-decision-making on behalf of children. If a parental decision is judged contrary to the child's best interest, the state is justified in interfering with that decision. As a result, the best-interest standard has also become the standard by which physicians and parents are expected to make decisions on behalf of children and the standard by which physicians judge parental decisions in determining whether state intervention might be necessary.[22]

Brock and Buchanan define best interest as "acting so as to promote maximally the good of the individual."[23] Beauchamp and Childress define the best interest standard 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."[24] In both cases, the standard requires the surrogate to act so as to always make the decision most favorable to the child.

However, for a number of reasons, the best interest standard proves difficult to apply and may provide little meaningful guidance in practice.[25] First, it may be difficult to precisely define the "best interest" of a child, and controversy may surround that determination. The best interest standard is most easily applied in situations where a child's life is jeopardized and where death can be averted with easy, safe, and effective treatments. Thus, little controversy exists regarding the use of blood transfusions for children in life-threatening situations. However, in situations involving less serious threats to a child's health, as in the case of cleft lip and palate repair, it may be more difficult to determine whether parental refusal of permission violates the standard.[26]

Second, the notion of "best interest" is inherently a question of values, and most parents believe they are making a decision in the best interest of their child. Parents who are Jehovah's Witnesses, for example, may truly believe that they are making a decision in the best interest of their child when they refuse to consent to a blood transfusion. Loss of salvation is not, after all, a trivial consequence of acting on the physician's recommendation. Most medical and legal assessments of these cases, however, ignore the theological consequences in making a best interest determination. Appealing to a best interest standard does not help the courts decide whose conception of the child's best interest should prevail.[27] Ultimately, these are not objective "best interest" cases, but involve assessments of which values should carry the most weight. They pit the state's determination of "best interest" against that of the parents.[28]

Third, the nature of interests are frequently complex. Although medical considerations are important, a child's interests will also be affected by emotional and physical accompaniments of the chosen course. Best interests all too frequently may be reduced to objective medical interests alone. In discussing chemotherapy for a child with leukemia, for example, medical professionals frequently focus on the fact that therapy will increase the child's chance of survival while underestimating the negative aspects of cancer treatment. Some parents 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. Determining how these multiple factors ought to be weighed is no simple matter.

Finally, it is not clear that the best interest of the child should always be the sole or primary consideration in treatment decisions.[29–31] There are few situations in which society actually requires parents to always act in a way that is optimal for their children. In seeking to optimize family welfare, parental decisions may commonly subjugate the interests of individual children, and while the state can certainly intervene when parents endanger their children, it is not justified in intervening simply because parental decisions may compromise the interests of a child in favor of those of the family.[32] For example, few would argue that a college education would not be in the best interest of most children. Yet we do not require parents to provide their children with a college education. Nor do we require parents to send their children to the best elementary schools. Murray argues that while avoiding harm is important, parents are not obliged to elevate avoiding harm to children above all other goods. Parents are not required to go to all lengths to avoid every conceivable harm: we do not require or expect parents to barricade children in their yards to avoid contact with neighborhood dogs, bullies, or runaway cars.[33] Given the risks of driving, it is most certainly not in the best interest of my children to put them in the car so that I can get my morning coffee at Starbucks® and pick up a video to watch later in the evening. Yet few would argue that I have an obligation to forgo those opportunities simply because they put my children at some measurable risk. We also regularly grant parents the freedom to make medical decisions that most people would argue are inferior to other alternatives and allow them to limit the choices and actions of their children for reasons that are not always out of concern for the child's interests.[34] John Lantos argues that "The interests of children are neither absolute nor unambiguous. They are always intertwined with the interests of others, and often must be weighed against those other interests."[35] In reality, few parents can attain the ideal represented by a best interest standard, since the interests of one child will at times conflict with the interests of others within (and outside of) the family in ways that require parents to balance the importance of the competing interests, at times subjugating the interests of one or more children.[36] Conceptually, isolating a child from the familial context would simply suppress other legitimate interests.[37]

While many physicians, ethicists, and judges appeal to a best interest standard in making judgments about parental decisions regarding children, they frequently modify the standard significantly in practice to accommodate the concerns cited above. Those who attempt to apply the standard literally will frequently appeal for state intervention in situations that many would consider to be inappropriate. Continued reference to a best interest standard simply confuses physicians and others who must determine when parental refusals of consent should be tolerated and when state intervention should be sought. While state decisions concerning the disposition of children in custody disputes may apply a best interest standard, the actual standard applied to parental decision-making appears to be a different one.[38]

In practice, it appears that the standard applied to parental decision-making for children is not truly a best interest standard, but rather something else. Several authors suggest that rather than identifying which one of several options is in the best interest of the child, we should identify a range of acceptable options within which parents can reasonably choose, and that parents should be granted some leeway in making decisions for their children.[39] In the medical setting, courts have frequently placed a high burden on the state to show that medical treatment is necessary before compelling treatment over parental objections, and the state is most likely to interfere with a parent's decision when the child is suffering from a serious and potentially life-threatening illness or injury that can be readily managed with medical treatment.[40] The state must establish that parental choices endanger the child and thus fall below the acceptable threshold.[41] In general, courts have gone against parents when the life of a child is endangered, but have typically given great discretion to parents in situations that are not imminently life-threatening.[42] Holder summarizes the legal standing: "the rule has evolved that in a high risk procedure where the condition itself will not immediately threaten a child's life, courts are inclined to abide by the concept that establishment of 'priorities of risk' is a legitimate parental function, even though child protection authorities, school personnel, or physicians would have chosen the other alternative."[43]

In many discussions of the best interest standard, an effort is made to identify a threshold other than best interest below which state intervention would be justified. Kopelman argues: "A morally and socially defensible policy presupposes a justifiable threshold of adequate parenting." She further states "The best-interests standard…does not require us to act in accord with what is literally best for a child, ignoring all other considerations, or even to presuppose that there is always one best solution shaping duties or guiding actions. Rather, it requires us to focus on the child, and select wisely from among alternatives, while taking into account how our lives are woven together."[44] Yet this no longer seems to be a *best* interest standard but some other threshold. Deville and Kopelman argue that "Coercive state interference with parental prerogatives, for the good of the state and the good of the child, is justified when there is 'clear and convincing evidence' that parents' actions or decisions represent likely and serious harm to the child."[45] Likewise, Sher points out that neglect, the basis for state action in many medical cases, has been defined as a failure to provide "the minimum quality of care which the community will tolerate."[46] These commentators seem to be suggesting not a best interest standard, but rather a harm-based standard for intervention. The real question is not so much about identifying which medical alternative represents the best interest of the child, but rather about identifying a harm threshold below which parental decisions will not be tolerated. Referring to a best interest standard merely confuses the matter. I would suggest that the Harm Principle represents the proper legal and ethical basis for state intervention in these cases, and that the Harm principle is consistent with the threshold level suggested by most commentators and applied by most courts.

THE HARM PRINCIPLE AND STATE ACTION

The government's authority in the health arena arises primarily from its constitutionally sanctioned "police power" to protect the public's health, welfare, and safety.[47] The ethical basis for the exercise of these police powers lies in what has become known as the "harm principle." In *On Liberty* John Stuart Mill argued that "The only purpose for which power can rightfully be 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."[48] In his work to establish a group of "liberty-limiting principles" that enunciate types of considerations that are always morally relevant reasons to support state action, Joel Feinberg has further refined the principle by arguing that to be justified, restriction of an individual's freedom must be effective at preventing the harm in question and no option that would be less intrusive to individual liberty would be equally effective at preventing the harm: "It is always a good reason in support of penal legislation that it would be effective in preventing (eliminating, reducing) harm to persons other than the actor (the one prohibited from acting) *and* there is no other means that is equally effective at no greater cost to other values."[49]

The harm principle provides a basis for identifying the threshold for state action. The characteristic of parental decision-making that justifies interference is not that it is contrary to the child's best interest, but rather that the decision poses some harm to the child. State authorities may therefore be justified in interfering with parental decisions regarding the health care of children in two situations, both of which fulfill the harm principle. First, intervention may be justified under the *parens patriae* doctrine. Under this doctrine, states have the authority to protect and care for those who cannot care for themselves and may intervene when there is evidence that parental actions or decisions are likely to harm a child. Second, intervention may be justified as an exercise of government's police powers when intervention is necessary to protect the health of the population or others. This paper focuses on the first of those justifications.

The *parens patriae* doctrine recognizes that society has an obligation to ensure that the basic needs of its most vulnerable members are met. In general, parental decisions should be accepted except in those rare cases where the decision of a parent places the child at substantial risk of serious harm. In these cases, the state acts *in loco parentis*, in the place of the parents. While this role of the state has been recognized as constitutionally valid, in the U.S. courts have closely examined such actions, showing reluctance to require medical treatment over the objection of parents "except where immediate action is necessary or where the potential for harm is rather serious."[50]

Having identified the harm principle as a basis for state action, the next step is to further define the harm threshold by identifying the level of harm to be tolerated in parental decisions. It seems clear that not all harms should trigger state intervention. As we discussed earlier, parents should be given some leeway in making decisions for their children, even when those decisions may pose some small degree of risk to the child. Parents will from time to time have to make decisions that "harm" one child in order to benefit the family or meet the needs of another child. Lainie Ross has suggested what she calls a model of constrained parental autonomy that 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: abuse, neglect, and exploitation are prohibited, and children must be provided with goods, skills, liberties, and opportunities necessary to become autonomous adults capable of devising and implementing their own life plans.[51] Ross modifies the promotion of best interests to the promotion of basic interests. Another way of understanding Ross, however, is that state intervention should be limited to cases in which children are placed at the level of harm that occurs when they are deprived of basic needs. In another article, Ross has argued that state intervention is justified when parental refusals are life-threatening or place the child at high risk for serious and significant morbidity and the treatment is of proven efficacy with a high likelihood of success.[52] Others have come to similar conclusions regarding the harm threshold for state intervention. Several of these have further refined the definition of serious harm to include loss of life, loss of health, loss of some other major interest, and the deprivation of basic needs.[53] Feinberg suggests that serious harm includes interference with interests necessary for more ultimate goals like physical health and vigor, integrity and normal functioning of one's body, absence of absorbing pain and suffering or grotesque disfigurement, minimal intellectual acuity, and emotional stability.[54] Dworkin appeals to Rawls' conception of justice and argues that we ought make decisions for children that "preserve their share of what Rawls calls 'primary goods'; that is, such goods as liberty, health, and opportunity, which any rational person would want to pursue whatever particular life plan he chooses."[55] 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.[56]

While these suggestions vary somewhat, they do hold in common the notion that state intervention should not be trivial but should be triggered when a parental decision places the child at significant risk of serious harm. For the medical professional facing a parent refusing to consent to a suggested course of treatment, the proper question is not, "Is this intervention in the child's best interest?" but rather "Does the decision made by the parents significantly increase the likelihood of serious harm as compared to other options?" Parental decisions that do not significantly increase the likelihood of serious harm as compared to other options should be tolerated.

JUSTIFYING STATE INTERVENTION: EIGHT CONDITIONS

Having identified a reasonable justification for state intervention in the harm principle and further refined the tolerable harm threshold for parental decisions as an increased likelihood of serious harm as compared to other options, we must still deal with several procedural issues. Building on Feinberg's discussion of the harm principle,[57] I would propose that the following eight conditions (see Table 1) must be met before considering the use of state intervention to require medical treatment of children over parental objections.

Table 1. Conditions for Justified State Interference with Parental Decision-making.

1 By refusing to consent are the parents placing their child at significant risk of serious harm?
2 Is the harm imminent, requiring immediate action to prevent it?
3 Is the intervention that has been refused necessary to prevent the serious harm?
4 Is the intervention that has been refused of proven efficacy, and therefore, likely to prevent the harm?
5 Does the intervention that has been refused by the parents not also place the child at significant risk of serious harm, and do its projected benefits outweigh its projected burdens significantly more favorably than the option chosen by the parents?
6 Would any other option prevent serious harm to the child in a way that is less intrusive to parental autonomy and more acceptable to the parents?
7 Can the state intervention be generalized to all other similar situations?
8 Would most parents agree that the state intervention was reasonable?

First, as discussed above, the parental decision to deny treatment will place the child at significant risk of serious preventable harm.[58] This seems an appropriate threshold for state intervention. To justify state intervention, the parental decision must present a non-trivial risk of a serious harm. To justifiably interfere with the parental decision, some other course of action must be available that would allow prevention of the harm to which the parental decision exposes the child. A critic might argue that terms like significant and serious are subjective and in that sense do not represent an improvement over the subjectivity of "best interest." I would counter that there will always be an interpretive element in judging whether a parental decision crosses the threshold for state intervention. As we wrestle with whether state intervention should be invoked, however, it is most important that we be guided by the correct standard in our discussions. The biggest problem with a best interest standard is not its subjectivity, but 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. Discussing the child's "best interest" fails to focus on the relevant standard for determining when state action is justified. The harm standard focuses discussion in the proper place.

Second, the harm standard requires that the harm be imminent, requiring immediate action to prevent it.[59] When a parental refusal does not place a child imminently at significant risk of serious harm, state intervention should be postponed and attempts made to work with the child's parents or guardians in a non-confrontative manner to resolve the issue.

Third, the treatment plan rejected by the parents should be of proven efficacy. State intervention should not be elicited in cases where the rejected therapy is experimental or its benefit is conjectural.[60] Rather, state intervention should require that there be expert consensus, ideally supported by sound evidence, that interference with the parental decision and the provision of treatment has a high probability of being successful. Furthermore, the therapy should be likely to prevent, eliminate, or reduce the harm in question.[61]

Fourth, interference with the parental decision and provision of the treatment to which they object must be necessary in order to prevent serious harm from coming to the child in question.[62] If any acceptable alternative that is less intrusive to parental decision-making autonomy is available, that ought to be pursued in favor of state intervention.[63] For state action to be justifiable, all alternatives to interference with parental decision-making must have been explored and no morally preferable alternative found to exist.[64]

Fifth, interference with the parental decision must offer net benefit to the child.[65] The harm prevented must be more substantial than the harm that will result by interfering with parental choice. The potential harms of the resulting treatment must be considered along with the harm that results to family integrity by interfering with the parental decision. The intervention provided over parental objection must not itself place the child at high risk of significant harm. It must be clearly preferable to the course of action proposed by the parents, and it's projected benefits must outweigh it's burdens.

Sixth, the extent of state intervention and the treatment allowed under the authority of the state should represent the least intrusive alternative that will reduce harm to the child and minimize the impact on parental authority. Most of the time removal of the child from the home will not be necessary, and should not be contemplated unless every other possibility has been considered. Likewise, treatment over parental objections should include only that which is necessary to prevent harm to the child.

Seventh, the pursuit of state intervention must be generalizable and impartial in the sense that all similar cases would also result in state intervention. The decision to seek state intervention should not be influenced by morally irrelevant considerations (i.e., the religious nature of the decision). For example, state intervention in the case of refusal to consent to a blood transfusion is justified not because the parental refusal has a religious basis, but because the parents are refusing a potentially life-saving therapy that meets the conditions above. A parent's reason for the decision should not be a factor in whether state intervention is sought. Rather, the likely outcome of their decision is the only relevant factor: is it likely to result in serious harm to a child.

Finally, the decision to seek state intervention must pass the test of publicity: the anticipated outcome of state intervention is what other parents would agree is appropriate for all children – that they be provided a chance for normal healthy growth or a life worth living.[66]

THE HARM PRINCIPLE APPLIED

The final section of this article will attempt to apply the eight requirements of the harm principle to some of the common cases encountered in pediatric practice. Legal precedent seems most clear for cases that involve medical treatments that are proven to be efficacious, pose little medical risk, and offer significant benefit by preventing the harm of death. Two common examples include parents of the Jehovah's Witness faith who refuse to consent to a blood transfusion for a child and parents of the Christian Science faith who refuse to provide insulin to a child with diabetes. There is consistent agreement among medical professionals and the courts that state intervention is justified in these cases.[67] These cases satisfy the eight conditions of the harm principle rather easily. In both situations, withholding treatment (blood or insulin) represents a significant risk of serious harm (i.e., death). Treatment is necessary to prevent harm befalling the child, and treatment is of proven efficacy. Treatment provides great benefit (prevention of death), imparts minimal risk of harm, and represents proportionately greater benefit than harm to the child. State intervention is justified in all similar cases, and is not restricted solely to those cases in which the parents refuse treatment on religious grounds. For example, if a parent refused because of their concern about the potential for tainted blood being introduced into their child, state intervention would still be sought (because the potential for harm to the child does not differ). Finally, the decision to intervene in these situations can be defended in the public forum and will most likely be overwhelmingly supported. Those six criteria support state intervention in these paradigmatic cases. The remaining two criteria serve to modify state action by requiring the need for action to be imminent and the consideration of alternatives that might be acceptable to the parents. In the case of blood transfusion, some situations would demand immediate action, others might allow time for a consideration of bloodless treatment alternatives or a more extended discussion involving church elders that might result in an agreement regarding treatment. In both cases, if an alternative acceptable to the parents that will also prevent harm to the child can be identified, it should be pursued first.

What of parental decisions that expose a child to serious harms, but do not place a child at risk of death? A child with cancer suffering intensely from pain because his parents will not allow the use of pain medication for fear that it will kill their child suffers a serious and immediate harm. The child's pain is easily and safely treatable with medications that have been studied extensively and proven efficacious. Those medications provide a benefit that far exceeds any risk. In this case non-pharmacologic methods of pain control (like hypnosis) may be more acceptable to the parents and should be pursued, but if narcotics prove necessary to achieve adequate pain relief, they should not be withheld, and state intervention is justified to assure that the child receives adequate relief from pain.

What of those situations in which a parent refuses a therapeutic intervention that poses greater potential risk to a child than either a blood transfusion, insulin, or pain medication? Colin Newmark was a young boy with Burkitt's Lymphoma from the State of Delaware in the U.S. whose parents (Christian Scientists) refused to consent to a regimen of chemotherapy that would provide Colin with less than a 40% chance of survival. Delaware's Division of Child Protective Services intervened and wanted to authorize treatment over the objection of the parents. The Delaware Supreme Court rendered the opinion that the parents' decision ought to be respected. In so doing, they distinguished Colin's case from others like those above by pointing to the low likelihood of success (less than 40%) and the high level of risk and burden entailed in the treatment being offered.[68]

Looking at the Newmark case from the perspective of the harm principle, the first question we ask is whether the decision to refuse chemotherapy placed Colin at significant risk of serious harm. The answer would appear to be yes. By refusing treatment, Colin's chance of death (a serious harm) goes from 60% to 100%, a significant increase in risk. Was the harm imminent? While treatment did not need to be started within the hour, a delay of more than a few days would place Colin at greater risk, further reducing the chance of successful therapy. Nonetheless, it did leave some time to try to resolve the situation through negotiation. Was treatment necessary to prevent the harm and was it likely to do so? In this case, the only proven treatment available was that offered by Colin's physicians: chemotherapy. It was the only treatment likely to treat Colin's tumor, and therefore necessary to prevent the harm of death. But did this treatment regimen offer Colin significant net benefit over his parent's choice of no treatment or did it simply replace one serious harm with another? This is where the Delaware Supreme Court could not justify state interference with the decision of Colin's parents. The Court argued that when a treatment offered only a 40% chance of survival and was itself "...extremely risky, toxic and dangerously life-threatening...," the treatment did not provide a great enough net benefit to justify the harm of interfering with parental decision-making and autonomy.[69] One could disagree with the court's assessment regarding this calculation, but for purposes of our discussion, it is sufficient to point out that the harm principle adequately focuses on the proper concern in this case: harm to the child. The court also properly focused on harm to Colin, not the religious motivation of his parents. Had the court decided to interfere with parental choice, the remaining elements of the harm principle would apply, including using the least restrictive means of preventing harm to the child. If any less toxic but similarly efficacious regimen were available that was more acceptable to the parents, it should have been offered. Furthermore, Colin should have been allowed to remain in the custody of his parents as long as they did not interfere with his treatment. Ultimately, however, this case illustrates that we should be reluctant to override parental wishes when therapy itself poses grave risks or limited likelihood of success.

A final example concerns parents who refuse to immunize their children with recommended childhood vaccines. Parents may refuse to immunize their children for a variety of reasons including religious proscriptions, naturopathic preferences and beliefs, or a rational calculation that remaining unvaccinated would be better for their children. This decision goes contrary to the very strong recommendations of most physicians and most pediatric organizations. Many physicians believe strongly that parental decisions to refuse immunization are contrary to the best interest of a child, and a few would argue that state intervention is justified on that basis. Most who feel this way appeal to the best interest standard.

But parents may also use the best interest standard in refusing immunization on behalf of their children. While most mandatory vaccines are effective and safe, a small possibility of adverse reactions exists. For example, a parent might reasonably conclude that refusing the measles vaccine is in the best interests of a child living in a community with a high immunization rate. In such a community, the prevalence of measles is sufficiently low that an unimmunized child would be unlikely to contract measles and therefore, could be safely spared any possible risks associated with the vaccine. In fact, it has been argued that "any successful immunization programme will inevitably create a situation, as the disease becomes rare, where the individual parent's choice is at odds with society's needs."[70]

Under what conditions would the harm principle support state intervention to vaccinate a child for the child's own sake?[71] In cases where the parental decision to refuse immunization places a child at significant risk of serious harm, state agencies may be obligated to intervene and provide the necessary immunization over the parents' objections. But in a well-immunized community, these situations will be rare indeed. A child lacking tetanus immunity who has sustained a deep and contaminated puncture wound might provide one example. Epidemic conditions might provide another. In both situations, state intervention for the child's sake can only be justified if the case can be made that the child is placed at significant risk of serious harm by remaining unimmunized. Routine childhood vaccinations have been proven effective at preventing disease and have a very low risk of serious side effects. But to justify their use against parental wishes, the need to vaccinate must be imminent, and must be necessary to prevent the harm. If the parents prefer an option that prevents the harm without vaccination (like quarantine) serious consideration must be given to that alternative. Even in the event of an epidemic or contact with an infectious agent that justifies immunization, it must be pointed out that only the immunization necessary to prevent the imminent harm can be justified. If the child has a deep contaminated wound that requires tetanus vaccine to prevent serious harm, the state is not justified in administering the chicken pox vaccine at the same time. With a few notable exceptions, the harm principle rarely provides sufficient justification for interference with parental decisions regarding immunization.

CONCLUSION

While there are good reasons for granting parents significant freedom in making health care decisions for their children, there are certain decisions that are sufficiently harmful that they ought not be allowed. The best interest standard has long been used to identify the threshold at which the state is justified in interfering with parental decision-making. In practice, however, parents cannot and should not always be expected to make decisions that are in the child's best interest. Using such a standard disallows other important considerations that might conflict with the child's best interest. The harm principle provides a foundation for interfering with parental freedom that more accurately describes an appropriate standard for interfering with parents who refuse to consent to medical treatment on behalf of a child. State intervention is justified not when a parental refusal is contrary to a child's best interest, but when the parental refusal places the child at significant risk of serious preventable harm.

NOTES

[1] *Union Pacific Railway Company v. Botsford*, US 141: 250 (1891).

[2] *Cruzan v. Director, Missouri Department of Health*, US 497: 261 (1990).

[3] Ibid.

[4] See for example *Meyer v. Nebraska*, US 262: 390 (1923), *Pierce v. Society of Sisters*, U.S. 268: 510 (1925), *Wisconsin v. Yoder*, US 406: 205 (1972), *Parham v. J.R.*, U.S. 442: 584 (1979), and *In Re Phillip B*, Cal Ct. App 156: Cal Rptr 2d 48 (1979).

[5] Joseph Goldstein, "Medical Care for the Child at Risk: On State Supervision of Parental Autonomy," in *Who Speaks for the Child: The Problems of Proxy Consent*, eds. Willard Gaylin and Ruth Macklin (New York: Plenum Press, 1982), pp. 153–190, here pp. 158–162.

[6] Allen E. Buchanan and Dan W. Brock, *Deciding for Others: The Ethics of Surrogate Decision-Making* (New York: Cambridge University Press, 1990), pp. 234–237.

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[10] Ibid., see also *Newmark v. Williams*, Del Super Ct 588: A.2d 1108 (1991).

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[17] Kathleen Knepper, cited at n. 14, 35.

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[43] Holder, cited in n. 42, above, 177.

[44] Kopelman, cited in n. 22, above, 276, 279.

[45] DeVille and Kopelman, cited in n. 8, above, 335.

[46] Sher, cited in n. 7, above, 165.

[47] Kenneth R. Wing, *The Law and the Public's Health*, 3rd edition (Ann Arbor, MI: Health Administration Press, 1990). See also Thomas E. Dover, "An Evaluation of Immunization Regulations in Light of Religious Objections and the Developing Right of Privacy," *University of Dayton Law Review* 4 (1979): 404–406, and Vorys, cited in n. 18, above, 815.

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[54] Feinberg, cited in n. 49, above, p. 37.

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[71] Note that the harm principle could also be used under very restrictive conditions (such as an ongoing epidemic) to justify state intervention to force immunization of children for the good of others in the community. In these cases, the unimmunized child represents a risk to others in the community, thus justifying state interference with parental decisions to withhold vaccination from their children. See Douglas S. Diekema and Edgar K. Marcuse, "Ethical Issues in the Vaccination of Children," in *Primum Non Nocere Today*, eds., G.R. Burgio and J.D. Lantos (Amsterdam: Elsevier, 1998), pp. 37–48.

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