a presentation to the Florida Bioethics Network in October 2008), have argued that a more useful (because it is less ambiguous) designator to use is "teenager," as the term is specifically delimited by age.

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Against the Tide: Arguments against Respecting a Minor's Refusal of Efficacious Life-Saving Treatment

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In October 1994, Billy Best, a 16-year-old adolescent from Boston, made national television skateboarding in Texas. Billy had been diagnosed with Hodgkin's disease earlier that year. After five sessions of chemotherapy, he had lost 20 pounds and his hair.[1] Billy had observed his aunt die after chemotherapy made her sick, and he too felt the chemotherapy was killing him. He decided to run away after he was told that most of the cancer was gone, but that he would need to continue chemotherapy and receive radiation therapy over the next four months.[2]

A self-described born-again Christian, Billy packed his skateboard and $300 into a small duffle bag, left home, and "put his life in God's hands."[3] His parents, heartbroken and stricken with fear, made an appeal in the national media for him to come home and promised not to force more chemotherapy on him.[4] When Billy returned from Houston to Boston, he and his parents met with the oncologists and explained that they would seek out complementary and alternative medicines (CAM) and use prayer. The physicians reported the family to the Department of Social Services, which tried to have Billy removed from his parents' custody and to have treatment forced upon him.[5] The State of Massachusetts dismissed the case after intense media coverage of the case.[6] Although initially the claim was that Billy would probably die without treatment,[7] the physicians eventually acknowledged that he had received enough chemotherapy that he had a good chance of survival.[8] Billy and his family, on the other hand, claim that he was cured by the CAM and prayer.[9]

Fourteen years later, Billy is, according to his own web site, healthier than ever.[10] He takes two to four ounces of Essiac a day "to keep his immune system boosted" and also does at least two 21-day cycles of 714X per year for the same reason. Billy avoids processed food, red meat, dairy products, and sugar and takes lots of Shaklee supplements. He also continues to enjoy skateboarding. On his web site are links to his book, published by his parents, and to 714X and Essiac herbal formula.[11]

Billy Best is not the only adolescent to make the media for treatment refusal. In 2005, 15-year-old Starchild Abraham Cherrix was diagnosed with Hodgkin's disease.[12] He underwent chemotherapy but was told in 2006 that

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the cancer had returned. He refused a second round of chemotherapy and the recommendation to add radiation treatment. Instead he and his father traveled to Mexico to try the Hoxsey method,[13] a combination of an herbal tonic and organic diet. Upon their return, his parents were accused of medical neglect and he was ordered by a judge to undergo chemotherapy.[14] Eventually a compromise of radiation therapy plus CAM was approved by the courts.[15] In February 2007, the Virginia state legislature passed what has come to be known as "Abraham's Law," which allows teenagers 14 years or older and their parents to refuse medical treatments for cancer and other diseases.[16] Today, Abraham is still fighting his cancer and remains optimistic that he will win the battle.[17]

In November 2007, Dennis Lindberg, a 14-year-old Jehovah's Witness with leukemia, was granted the right by a Washington State court to refuse a blood transfusion, even though the refusal was expected to kill him.[18] Dennis was supported by his aunt and legal guardian, Dianna Mincin, who is also a Jehovah's Witness. Less than 12 hours later, Dennis was dead.[19]

The trend is clear: The courts and state legislatures are becoming more tolerant of permitting refusal of efficacious treatment for minors (any individual younger than 18 years) with life-threatening illnesses, particularly when the minor and parents (or legal guardians) are in agreement.[20] In this article, I will argue why the courts and state legislatures are mistaken in their policies to respect family refusals of well-established, highly efficacious medical treatment for adolescents with life-threatening illnesses like childhood leukemia and lymphoma. For the purposes of this article, I consider a treatment "highly efficacious" if there is a greater than 75% chance of cure (75% overall survival) with the proposed medical treatment. The issue of line drawing will be discussed in the section "Pediatric Decisionmaking for Life-Threatening Illnesses When Effective Therapy Does Not Exist," below.

Adult versus Pediatric Decisionmaking with Respect to Effective Life-Saving Therapies

Imagine Steve has low-risk acute lymphoblastic leukemia (ALL) that has a 90% overall survival. (How decisionmaking is modified when treatment is less effective is addressed in the section "Pediatric Decisionmaking for Life-Threatening Illnesses When Effective Therapy Does Not Exist," below.) The physician recommends chemotherapy and blood transfusions as necessary. If Steve is an adult, then the wishes of the competent adult are decisive on procedural grounds: The competent adult has the right to accept or refuse all treatment, including life-saving treatment (Table 1).

However, if Steve is a minor, traditionally his parents would be expected to make decisions for him. If parental autonomy to make healthcare decisions for a child were absolute, the response to the parents' wishes would look the

Table 1. Decisionmaking by Competent Adults with Respect to Effective Life-Saving Therapies

Adult's preferences	Yes	No
Physician's actions	Treat	Do not treat; try to convince but in the end, respect patient's wishes.

same as in Table 1: Physicians would treat when parents authorized treatment on behalf of their child and would not treat when parents refused. But parents, as surrogate decisionmakers, are held to a "best interest" standard. Although the presumption is that parents know what is best for their child, the state has the authority to intervene when the parents' decision falls below some threshold that qualifies their decision as abusive or neglectful. This is permitted because the child is not only a member of a family but also a member of a larger community, and the state has the authority to intervene when the parents fail to protect members of their family who are also community members. Thus, if Steve has a life-threatening illness for which an effective treatment exists, his parents' failure to authorize treatment is generally regarded as neglectful, and the state would take custody and consent for treatment (Table 2). However, as the treatment becomes more drastic (e.g., involves amputation) or less successful (e.g., the likelihood of overall survival is <10%), physicians may not seek court intervention. Even if the physicians seek court intervention, whether the state would or should override the parents is more ambiguous (discussed in the section "Pediatric Decisionmaking for Life-Threatening Illnesses When Effective Therapy Does Not Exist," below).

Some may object that if Table 2 is valid, then pediatric decisionmaking is not about respecting parental autonomy. Table 2 shows that parents can authorize effective life-saving treatment and have their permission respected, but they cannot refuse or their decisions are overridden. The objection is that the parents do not really have decisional authority, because authority to make the "right" decision is not authority at all. Nevertheless, even if parents do not have substantive decisional discretion, consent is needed and the physicians will seek parental consent first. If the parents refuse, physicians will often work with the parents to convince them to do otherwise and only seek legal intervention as a last resort. The belief is that the parent's consent is not just symbolic but is consistent with the respect that we give to parents in their authority over their child's life.[21]

The difference in how a refusal is handled in Tables 1 and 2 represents the difference in who determines what is in the patient's best interest. In adult medicine, a competent patient has the right to accept or refuse any treatment, including life-saving treatment. The solution to physician–patient disagreement is procedural: Physicians must respect the competent patient's wishes because it is presumed that the competent patient knows what is best for himself. This does not mean that the physician should accept all refusals as final, but after attempts at convincing the patient to change his mind, the physician must ultimately respect his refusal. A competent adult's decision is respected because, even if the physicians are sure that a medical treatment would serve the patient's medical best interest, physicians do not know what is best for any particular patient, all things considered. Steve may be a Jehovah's

Table 2. Decisionmaking for Children by Parents with Respect to Effective Life-Saving Therapies

Parents' preferences	Yes	No
Physician's actions	Treat	Court order to treat over parental objections

Witness and refuse treatment on the grounds that accepting blood will damn him for eternity, or Steve may refuse treatment because he believes that he can be cured with less toxic medicines as prescribed by his CAM provider. Either decision reflects his own evaluation of what is best for him, all things considered.

In pediatrics, determining who is the appropriate decisionmaker is more complex. Traditionally, parents were presumed to be the decisionmakers, but this presumption is being challenged in two ways. First, it is challenged if the physicians believe that the parents are not acting in the child's "best interest," or, more accurately, if they believe that the parents' refusal is neglectful or abusive. In these cases, the state may be asked to take medical custody of the child and override the parents' refusal. More recently, parental authority is being challenged by those who seek to empower minors with healthcare decisionmaking autonomy.[22] The trend to respect adolescent autonomy means that Table 2 must be reconsidered in light of the minor's own preferences. Table 3 provides labels to represent each potential decisionmaking scenario.

Pediatric Decisionmaking with Respect to Effective Life-Saving Treatment

Now imagine our patient Steve with cancer is 6 years old. There are very few who would argue that a 6-year-old boy has the capacity to understand what it means to have a diagnosis of cancer and what the proposed treatments entail. Few would argue that Steve could make an independent assessment of the risks, benefits, and alternatives of treatment. Therefore, as depicted in Table 4, the preferences of the child has a minimal role in the decisionmaking process. The reasons for acceding to a parent's wishes to treat are respect for parental autonomy and the parents' ability to assess what is best for the child. The parents' decision is overridden when they refuse life-saving treatment because their action is determined to be neglectful, and this holds regardless of the child's stated preference for or against treatment.

Table 4, however, is no different than Table 2: Parental permission is respected and refusal is overridden by court intervention. The child's own opinion about treatment or refusal has no impact on the outcome, even if it might have some impact on the process (particularly with minor refusal).

Now consider the trend to support adolescent autonomy in healthcare decisionmaking that is justified on the grounds that some adolescents are "mature minors" who know best what is in their best interest.[23] A "mature minor" refers to someone who has not reached adulthood (as defined by state law), but who may be treated as an adult for certain purposes (e.g., consenting to certain types of medical care). Mature minor statutes now exist in many states and courts have frequently sided

Table 3. Decisionmaking with and on Behalf of Children with Respect to Life-Saving Therapies

		Minor's preferences	
		Yes	No
Parents' preferences	Yes	Best interest	Minor refusal
	No	Parental refusal	Family refusal

Table 4. Decisionmaking with and on Behalf of Children with Respect to Effective Life-Saving Therapies

		Minor's preferences	
		Yes	No
Parents' preferences	Yes	Treat. Respect for parental authority in defining a child's best interest. Good to have the child on board.	Treat. Respect parental wishes on the grounds of the minor's best interest and the child's immaturity. Try to convince the child to see the utility of treatment.
	No	Treat with court order. Parents are failing to provide for their child's basic interests, which is medical neglect. Good to have the child on board.	Treat with court order. Parental medical neglect. The fact that the child agrees with parents is not perceived to be an independent decision.

with the mature minor's right to define his own best interest and to make his own healthcare decisions.[24] Thus, it may be more accurate to state that medical decisionmaking for children historically was understood by Table 4, but that Table 4 now only applies to immature and/or young children.

If adolescents are deemed "mature" and are allowed to make decisions based on their own judgment of what is in their best interest, the decisionmaking process would empower the adolescent to make healthcare decisions just like his adult counterpart. The algorithm for Steve at age 16 years if he were granted decisionmaking authority, then, would be depicted by Table 5. It demonstrates that the parent's preferences serve an advisory function for the child, but only to the extent that the minor is willing to involve his parents, regardless of the fact that he lives in their house, they pay the healthcare bills, and they have responsibility for providing for their child's basic needs.[25] And when the parents' duty to promote their child's basic needs conflicts with the minor's right to define his own best interest, the minor's right would trump.

It is important to realize how Tables 4 and 5 differ. The presumption of Table 4 is that parents have authority to act in the child's best interest, and when they fall short by failing to provide for their child's basic medical needs, that the state will promote the child's "best interest" (i.e., the child's basic medical needs). In Table 5 the presumption is that the mature minor knows what is best and is acting in his own best interest and that his judgment trumps third-party duties to protect his basic needs. That is, the mature minor is being given the same decisional authority as the adults in Table 1.

Although the scenarios in which the minor seeks treatment (best interest and parental refusal) lead to treatment in both Tables 4 and 5, the justifications that support the decision to treat differ. When the child and parent consent to treatment (best interest), the focus in Table 4 is that the parents have appropriately defined the child's best inter-

Table 5. Decisionmaking with and on Behalf of Teenagers with Respect to Life-Saving Therapies (Algorithm **IF** Mature Minor Were Granted Decisionmaking Authority)

		Adolescent's preferences	
		Yes	No
Parents' preferences	Yes	Treat. Minor defines his own best interest. Good to have the parent's support.	No treat. Adolescent can make his or her own decisions, and his right to do so trumps his parents' duty to promote his basic needs.
	No	Treat on the grounds that the teen is a mature minor. Can try to help parents understand the minor's judgment.	No treat. Adolescent can make his or her own decisions. Strengthened by parents' agreement (although should be unnecessary).

est and the child's agreement facilitates the treatment. In Table 5, the focus is that the minor has best determined his best interest and his judgment is corroborated by his parents' support. When the minor consents to treatment and the parents refuse (parental refusal), the reason for treating in Table 4 is that the parents are neglectful and they must be overridden, whereas in Table 5, the argument is that the minor has defined his best interest and the physician and his parents' should respect his autonomy. Attempts can be made to convince the parents to support their adolescent's decision, but if they continue to refuse, the physicians can treat based on the adolescent's consent.

Tables 4 and 5 have different outcomes in the scenarios in which the minor objects to treatment (minor refusal and family refusal). In actuality, in the case of minor refusal, most physicians would side with the parents and treat the minor over his objections, regardless of the minor's age. That is, most physicians would act according to Table 4 and not Table 5. This is not to say that physicians and parents would just ignore the adolescent. They would seek to get his support and to convince him to get treatment. Although the physicians and parents would do this for all children, they would be even more willing to engage a mature child and to use arguments and reasoning that are appropriate to his maturity.[26] But if a stalemate remained, the adolescent would get treated unless he could convince his parents and the physicians that the treatment was unnecessary. The minor could also avoid treatment by running away, like Billy Best.

So what does this mean about decisional authority? On first glance it suggests that the practice of respecting the mature minor does not hold when the minor has an available parent who concurs with the physicians. However, recall that in cases of parental refusal, the physicians will support the adolescent and take the parents to court, and the parents' decision will not be respected. That is, it seems that the physicians are not really respecting a procedural method of determining who best speaks for the minor but, rather, are targeting a substantive goal: The physicians will support whoever consents to treatment (i.e., whoever agrees with them). But that is not about respecting autonomy or about shared decisionmaking, but about making the "right" decision; more specifically, about making the same decision as the physicians.[27]

The case of family refusal, then, becomes the test case about decisional authority. Although physicians may respect adolescents and override parental objections on grounds of neglect in cases of parental refusal, and physicians may respect parents and override the minor's objections on grounds of immaturity in cases of minor refusal, in cases of family refusal, there is a minor saying that treatment is not in his best interest and his parents are in agreement. The physicians cannot claim to be respecting one party over the other. Rather, the physicians must either concede that the family knows what is best and respect its refusal or take the family to court to seek permission to override its refusal. And in more and more cases of family refusal with a mature adolescent, the courts are upholding the decision of the family. The courts may argue that their decisions are based on "mature minor" statutes, and 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.[28] 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. This is discussed further, below.

Actual Decisional Outcomes in Refusals of Effective Life-Saving Therapies

In Table 5, the cases of minor refusal and family refusal reveal how empowering minors with decisional authority would change pediatric decisionmaking, but Table 5 does not really reflect what happens in actual practice. What happens in reality is shown in Table 6: If the parents give permission for treatment, treatment is provided whether the minor agrees (best interest) or disagrees (minor refusal). There are two ways of arguing in support of treatment

Table 6. Decisionmaking with and on Behalf of Children with Respect to Effective Life-Saving Therapies (What Actually Happens)

		Adolescent's preferences	
		Yes	No
Parents' preferences	Yes	Treat. In the minor's best interest (as determined by parents and minor).	Treat. Parents define the minor's best interest. Minor can avoid treatment by convincing parents or by running away (Billy Best).
	No	Treat. Go to court on the grounds that parents are medically neglectful. Can also assert that the minor is acting as a mature minor.	Treat/no treat based on court ruling. Argue to treat based on both (1) that parents are neglectful and (2) that teen lacks decisional capacity to make an independent decision. Courts moving to respecting the teenager's decision. This is particularly true when the teen and parent agree.

in the case of minor refusal. One is to argue that the parents know what is best for the minor; the other is to argue that the child is not acting maturely. The minor can try to convince his parents that nontreatment is in his best interest (as in the case of Billy Best), but if he fails, treatment will occur. And yet, even if the minor convinces his parents to refuse treatment (family refusal), it is not clear that his and his parents' wishes will be respected. When Billy returned to Boston, attempts were made to charge Billy's parents with child neglect, to take legal custody of Billy, and to force him to undergo further chemotherapy. The case was dismissed, however, due to intense public pressure.

The courts' typical response to family refusal differs from their response to parental refusal. In the case of parental refusal, parents are often overridden by courts that find the parents neglectful. That is, the focus is less on parental authority and more about what is in the minor's best interest. When both minor and parent refuse (family refusal), the courts might still force treatment on young children on the grounds of what is in the child's best interest, but do not necessarily assert their authority to promote the adolescent's best interests, even if the result is that the minor, like Dennis Lindberg, dies from a treatable condition (compare family refusal in Tables 4 and 6, respectively).

One may argue that the different responses of the courts towards family refusal with a young child (override the refusal) versus with an older adolescent (respect the refusal) make sense pragmatically because it is more difficult to impose treatment on an unwilling teenager than on an unwilling younger child and because it is more difficult to take a teenager away from parents to force treatment because the teenager may run away. Morally, however, it is not clear that it makes sense. When parents refuse life-saving therapy, they are failing to promote their child's basic medical needs.[29] The fact that the minor agrees with his parents does not change the fact that treatment promotes his basic medical needs. Refusal of life-saving therapy may promote other interests and needs of the minor and his parents (e.g., religious beliefs), but basic needs have lexical priority over other needs and interests.[30] Therefore, effective treatment for a life-threatening illness must be provided even if it requires overriding the minor's religious beliefs.

The case of minor refusal, on the other hand, shows the legal contradiction toward respecting "mature minors" because these cases rarely go to court. They do not get to court as the minor often does not have the wherewithal or means to challenge both his physicians and parents and insist upon a guardian *ad litem* to take him to court to promote his autonomy. Even if the minor gets to court, it is not clear that a judge would uphold the adolescent's decision to refuse treatment and die when he is pitted against his parents and his physicians, who seek treatment to save his life, which, they argue, is in the minor's best interest. Thus, the current pediatric decisionmaking model is inconsistent with the moral principle of adolescent autonomy with which it is justified. Although it is claimed that a mature adolescent's autonomy should be respected because a mature adolescent knows what is in his own best interest, the fact is that the mature adolescent's autonomy is overridden when his actions are against his parents' perception of what is in his best interest (minor refusal). Rather, the adolescent is only heard when he agrees with his parents. An alternative decisionmaking model and/or moral principle is needed.

Constrained Parental Autonomy

Elsewhere I have developed a model of decisionmaking for pediatrics that I called constrained parental autonomy.[31] The model presumes that parents should have the authority to make life-saving treatment decisions for their children. Parental authority, however, is not absolute but is constrained by the respect that is owed to the child. There is both a positive and negative conception of respecting the child. The negative conception has lexical priority and requires that parents not harm their child's basic needs. The positive conception requires that parents help their child develop the skills to become an independent and autonomous decisionmaker when he attains adulthood. But the positive conception is not limited to the child's future needs and interests, but also requires respect for the minor's present projects, although not to the extent that we would respect these projects if they were the goals of a competent adult.[32]

What does this mean for the minor and his role in the decisionmaking process regarding life-saving treatment? Few would argue that at age 6, Steve could make an independent assessment of the risks, benefits, and alternatives of treatment. Therefore, the preferences of the young child play a minimal role in the decisionmaking process as depicted in Table 4. The reasons for acceding to the parent's wishes to treat are respect for parental authority and respect for the parents' ability to assess what is best for the child. The parents are overridden when they refuse treatment because their actions fail to promote the child's basic needs and are therefore neglectful. This is true regardless of the child's preferences. Although the young child's voice is overridden as immature, this does not mean we do not try to cajole him into accepting the situation. It means, however, that the child's preferences for or against treatment are nonbinding, even if they are a signal to both the parents and the physicians that the child needs further education and support.

But what about Steve at age 16? In the case of parental refusal, physicians treat Steve over his parents' objections because his parents are failing to promote his basic needs and only secondarily because Steve tells them that he wants treatment (i.e., that treatment is in his best interest). In contrast, in the case of minor refusal, physicians follow his parents' decision and treat Steve over his objections. This is not to deny that Steve may have some present projects that are thwarted, but his parents have an obligation to fulfill his basic medical needs before they can consider how and to what degree they should respect both his present and future projects. Steve can try to convince them otherwise. They should hold steadfast.

There are two arguments to justify overriding the decisions of a mature minor (minor refusal). The first argument is that the adolescent's current autonomy can be overridden to promote his long-term autonomy.[33] This is quite different from how adults are treated, but there are moral reasons for treating the decisionmaking capacity of adults and adolescents differently. The adolescent's relative lack of worldly experience "distorts his capacity for sound judgment."[34] In addition, adolescents need the opportunity to develop "enabling virtues" (habits, including the habit of self-control) that can advance their lifetime autonomy and opportunities.[35] Although many adults would also benefit from the development of their potential and the improvement of their skills and self-control, at some point (and it is reasonable to use the age of emancipation as the proper cutoff), the advantages of self-determination outweigh the benefits of further guidance and its potential to improve long-term autonomy.[36] Second, parental interest in raising their child according to their own vision of the good life does not abruptly terminate when the adolescent has achieved some degree of decisional capacity. If anything, his parents can now try to inculcate their beliefs through rational discourse rather than by example, bribery, or force.[37] In other words, the mature minor doctrine fails to acknowledge the limitations of judgment seen in many adolescents and the right and responsibility of parents to promote their adolescent's long-term autonomy. Adolescent maturity is necessary but not sufficient to justify sole decisionmaking authority in cases where effective life-saving therapies exist.

This is not to suggest that parents should not give their adolescent's opinions serious consideration, but only that parents should retain ultimate authority to consent to effective life-saving treatment over their adolescent's refusal until the age of emancipation. One could argue that even at emancipation the adolescent may benefit from parental input, but at some point, the value of making decisions for himself trumps his parents' authority to intervene even if it would promote his best interest, all things considered. His parents should attempt to convince him to act otherwise, but the refusal by an emancipated adolescent, like the refusal of any adult, must be respected.

How does the model of constrained parental autonomy address the case of family refusal? In this case, just as in the case of parental refusal, the parents are failing to promote Steve's basic medical needs. Thus, even though Steve and his parents may believe that the refusal promotes his present and future projects (positive conception), the physicians ought to seek court permission to treat because of the lexical priority of his basic medical needs. And the courts should impose treatment. Table 4 is the algorithm that the model of constrained parental autonomy generates for pediatric decisionmaking for life-threatening illnesses when an effective treatment exists for all minors regardless of maturity.

Pediatric Decisionmaking for Life-Threatening Illnesses When Effective Therapy Does Not Exist

In the case of a young child or adolescent with a life-threatening illness for which effective therapy exists, the model of constrained parental autonomy does not give any decisional authority to the minors and gives only modest decisional discretion to parents. However, if we were to consider the case of a life-threatening illness for which treatment is not highly effective (e.g., prognosis is <10% overall survival) or an illness for which only experimental treatment exists, then parental discretion and the adolescent's dissent would have a more determinative role. Table 7 depicts the algorithm that the model of constrained parental autonomy generates for minors with life-threatening illnesses when therapies have low efficacy or are experimental.

As in all the previous algorithms, when the parents and child want the proposed treatment, the treatment is provided under the best interest standard (best interest). Table 7 differs from Table 4, however, with respect to greater tolerance of refusals from either the mature adolescent or his parents. For example, although parental permission alone is sufficient to consent for effective life-saving therapy for a minor of any age, when parents want their child to undergo an experimental treatment

Table 7. Decisionmaking with and on Behalf of Minors with Life-Threatening Illnesses When Only Low Efficacy or Experimental Life-Saving Treatment Exists

		Minor's preferences	
		Yes	No
Parents' preferences	Yes	Treat. In the child's best interest.	Treat/not treat based on benefit-to-risk ratio and the maturity of the child.
	No	Do not treat. When possible, seek compromise.	Do not treat, particularly if the child is mature. When possible, seek compromise.

or treatment with a low probability of success, healthcare providers often seek the minor's assent, particularly of the older child. One could imagine the reluctance and even refusal of a physician to force such treatment on a mature adolescent (minor refusal). Thus, the case of minor refusal demonstrates that when the benefit-to-risk ratio decreases, the preferences of the mature adolescent have a greater role, although even the mature minor does not have sole decisional authority.

When the parents refuse low efficacious or experimental treatments, most physicians will respect the refusal given the benefit-to-risk ratio (parental refusal), even if the child would assent. Likewise, when both the parent and the minor refuse life-saving therapies of low efficacy (family refusal), the refusal is respected, particularly when the child is mature. Again, the justification is based on the lower benefit-to-risk ratio of the proposed treatment that does not justify forcing such treatment over the objections of the parents and the minor. In fact, if the physicians were to seek judicial intervention to override either a parental refusal or a family refusal on the grounds that even low efficacious treatment is in the child's best interest, it is not clear that the courts would or should find for the physicians. Although the courts are entrusted to promote the basic interests of its children citizens in its role as *parens patriae*, it may be appropriate to refuse to mandate a treatment that is unlikely to achieve its goal. The justices do not need to believe that the refusal is in the child's best interest, only that they may elect to demur when it is ambiguous whether treatment promotes the child's basic needs. This does not mean, however, that physicians must accept refusals at face value, because it is morally permissible to attempt to persuade the family to accept treatment, or at least to negotiate a time-limited trial.

The difficult practical and moral question, then, is when does the shift from highly efficacious treatment (Table 4) to inefficacious or experimental treatment (Table 7) occur. There exists great variability and disagreement within the medical profession about how ineffective a treatment must be before tolerance for pediatric refusals should occur. Other factors may also play an important role in deciding whether to respect a refusal: the likelihood of a good outcome without treatment, whether the condition is acute or chronic, whether the treatment is a one-time therapy or requires a protracted course of therapy, the invasiveness of treatment, whether the therapy can be provided as an outpatient or whether it requires one or more hospitalizations, to what extent treatment must be continued at home, and whether mandated treatment would require separating the child from his family.[38] Individual cases may require line drawing determined by the courts.

Reevaluation of the Three Cases

Let us return, then, to the three cases presented in the introduction. In the case of Billy Best, the physicians thought it was neglectful not to continue chemotherapy and asked the state to take custody of Billy so his course of therapy could be completed. The fact that the physicians were wrong in their prognosis is wonderful for Billy and humbling for the medical profession. But that should serve as a warning: Before attempting to retake custody, the physicians had the obligation to consider how much treatment Billy had received and how much greater benefit would accrue from continued treatment. Had they acknowledged that he had obtained most of the necessary treatment, they may have decided that the costs of going to court were outweighed by the marginal benefit that additional chemotherapy would provide. That is, they should have realized that the appropriate decisionmaking algorithm was Table 7 and no longer Table 4. In a sense, this is what happened when Starchild Abraham Cherrix and his parents went to court. Rather than having a court decide whether or not to force additional chemotherapy and radiation, the physicians, family, and the state came to a compromise that included both allopathic therapy (radiation) and CAM. It is not clear that Abraham's family would have agreed to any allopathic therapy without the legal ordeal and threat of losing custody, which is what disturbs Mark Mercurio. As he explains, "I am struck by the thought that if Abraham's Law had been in effect when Abraham's diagnosis was made, he might have died as a result"[39] because the law makes it more difficult for physicians to seek third-party intervention in protecting minors from themselves and their well-intentioned but misguided families.

The death of Dennis Lindberg should not surprise us given the use by the courts of the algorithm depicted in Table 6. Refusals by mature minors are respected when their parents support their refusal (family refusal). The mistake occurs in believing that we have an obligation to respect Dennis' autonomy or the autonomy of his guardians when their decision violates his basic medical needs. Rather, I have argued that Table 4 ought to be the guiding algorithm and that Dennis should have been treated over his refusal despite his guardian's support. The court's decision demonstrates a failure to provide effective treatment over family refusal that a coherent moral framework and analysis would demand. Again, this does not mean that all minors must be treated in all cases: As the likelihood of successful treatment decreases, whether the treatment promotes the child's basic needs becomes more ambiguous, and physicians and courts should respect broader discretion to a parental determination of the child's best interest (Table 7).

Conclusion

The evolving position of many courts, state legislatures, and healthcare providers to respect family refusals in cases of life-threatening illness when an effective treatment exists (Table 6) is morally inconsistent with our obligation to protect and promote the basic medical needs of minors (Table 4).

Basic medical needs have lexical priority over other interests and needs, both present and future regarding. Mature minor laws that permit refusals of effective life-saving treatments by adolescents alone (minor refusal) or in conjunction with their parents (family refusal) are morally unjustified.

Notes

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7. Hart J. Cancer patient beating odds. *The Boston Globe* 1999 Mar 7:B2.
8. See note 7, Hart 1999; Kong D. Specialists express concern over youth's cancer treatments. *The Boston Globe* 1995 Apr 7:Metro p. 25.
9. See note 5, Best, Best 2006.
10. See note 5, Best, Best 2006.
11. See note 5, Best, Best 2006.
12. The Abraham Cherrix story; available at http://www.angelfire.com/az/sthurston/abraham_cherrix.html (last accessed 14 March 2009).
13. Markon J. Fight over a child's care ends in compromise; Va. judge's order could have forced teen to get chemotherapy. *The Washington Post* 2006 Aug 17:A01.
14. See note 13, Markon 2006.
15. Craig T. Kaine signs tax cut for poor, medical rights for sick teens. *The Washington Post* 2007 Mar 22:B02.
16. Markon J. Update: Teen who fought cancer regimen feeling 'amazing'. *The Washington Post* 2006 Oct 15:C02.
17. Associated Press. Chemotherapy case: Teen who fought treatment is in remission. *The Washington Post* 2007 Sep 15:B05.
18. Black C. Boy dies of leukemia after refusing treatment for religious reasons. *Seattle Post-Intelligencer* 2007 Nov 29; available at http://seattlepi.nwsource.com/local/341458_leukemia29.html (last accessed 14 March 2009).
19. See note 18, Black 2007.
20. For the purposes of this document, the term "minor" refers to any individual less than 18 years old. The term "child" also refers to any individual less than 18 years, although I prefer to use the term "minor" when referring to all individuals under the age of 18 because "child" also contrasts with "adolescent" and the dual meaning of the term "child" can be confusing. However I do use the term "child" to refer to all individuals under the age of 18 when discussing the child's role and relationship with his or her parents.

    Some of the court decisions and Abraham's law use the age cutoff of 14 years to distinguish between children and adolescents, but mature minor statutes may include minors as young as 11 or 12 as "adolescents."
21. Buchanan AE, Brock DW. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge MA: Cambridge University Press; 1989:233–5; Ross LF. *Children, Families and Health Care Decision Making*. Oxford, UK: Oxford University Press; 1998:50–2; Goldstein J, Freud A, Solnit A. *Beyond the Best Interests of the Child* (new edition with epilogue). New York: The Free Press; 1979:7.
22. American Academy of Pediatrics (AAP), Committee on Bioethics. Informed consent, parental permission, and assent in pediatric practice. *Pediatrics* 1995;95:314–7; Alderson P. *Children's Consent to Surgery.* Oxford, UK: Open University Press; 1993; Weir RF, Peters C. Affirming the decisions adolescents make about life and death. *Hastings Center Report* 1997;27(6):29–40.
23. See note 22, American Academy of Pediatrics 1995; see note 22, Weir, Peters 1997.
24. Slonina MI. *State v. Physicians* et al.: Legal standards guiding the mature minor doctrine and the bioethical judgment of pediatricians in life-sustaining medical treatment. *Health Matrix* 2007;17:181–214; Derish MT, Heuvel KV. Mature minors should have the right to refuse life-sustaining medical treatment. *Journal of Law, Medicine & Ethics* 2000;28:109–24; Sigman GS, O'Connor C. Exploration for physicians of the mature minor doctrine. *Journal of Pediatrics* 1991;119:520–5.
25. Basic needs refer to primary goods as described by John Rawls (Rawls J. *A Theory of Justice*. Cambridge, MA: Belknap Press of Harvard University Press; 1971:62). Health is a primary good and medical care is one way to fulfill the child's basic medical needs. Parents have a duty to provide a threshold of healthcare services to ensure that the child's basic medical needs are met. See note 21, Ross 1998:5-6.
26. See note 21, Ross 1998:62.
27. Engelhardt HT Jr. Freedom vs. best interest: A

conflict at the roots of health care. In: Kliever LD, ed. *Dax's Case: Essays in Medical Ethics and Human Meaning.* Dallas, TX: Southern Methodist University Press; 1989:79.

28. Consider, for example, the case of *In re E.G.*, which was decided by the Illinois Supreme Court in 1989. EG was a 17-year-old Jehovah's Witness with acute lymphocytic leukemia who went to court to be allowed to refuse blood transfusions. The Court concluded that EG had the right to refuse blood transfusions but that she required her parents' concurrence (*In re E.G.*, 549 N.E.2d (Ill. 1989) at 328).
29. Again, as defined in note 25, health is a primary good, and medical care is one way to fulfill this basic need. When a child has a life-threatening illness for which effective treatment exists, parents authorize medical care to promote their child's basic medical needs. Sometimes, however, as discussed in the section "Pediatric Decision-making for Life-Threatening Illnesses When Effective Therapy Does Not Exist," below, treatment may not achieve cure and may cause more harm than good. In those cases, promoting the child's basic medical needs may mean refusing low-efficacy or experimental treatment and authorizing palliative care instead.
30. Rawls uses the term "lexical order" to refer to the requirement to satisfy the first principle before one can move to the second principle (note 25, Rawls 1971:42–3). Rawls explains that the correct term is "lexicographical order" but that this term is too cumbersome (note 25, Rawls 1971:43). Likewise, I hold that basic needs must be satisfied before one considers other needs and interests, and therefore refer to the lexical priority of basic needs over other needs and interests.
31. See note 21, Ross 1998:50–2.
32. See note 21, Ross 1998:66–9.
33. See note 21, Ross 1998:61–2.
34. Gaylin W. Competence: No longer all or none. In: Gaylin W, Macklin R, eds. *Who Speaks for the Child: The Problems of Proxy Consent.* New York: Plenum Press; 1982:35.
35. Purdy LM. *In Their Best Interest? The Case Against Equal Rights for Children.* New York: Cornell University Press; 1992:76-84.
36. See note 21, Ross 1998:61.
37. See note 21, Ross 1998:62; see note 34, Gaylin 1982:31.
38. Diekema DS. Parental refusals of medical treatment: The harm principle as threshold for state intervention. *Theoretical Medicine & Bioethics* 2004;25:243–64; Burt RA. Resolving disputes between clinicians and family about "futility" of treatment. *Seminars in Perinatology* 2003;27:495–502; Clark PA. Medical futility in pediatrics: Is it time for a public policy? *Journal of Public Health Policy* 2002; 23:66–89; Antommaria AH, Bale JF Jr. Ethical issues in clinical practice: Cases and analyses. *Seminars in Pediatric Neurology* 2002; 9:67–76.
39. Mercurio MR. An adolescent's refusal of medical treatment: Implications of the Abraham Cheerix case. *Pediatrics* 2007;120:1357–8.

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Response

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Lainie Ross's position can be summarized in the following two propositions:

1. For highly efficacious life-saving treatments: When a minor of any age has a life-threatening illness for which a "highly efficacious" treatment exists—where "minor" is any young person up to the age of emancipation—she should receive it, whatever she or her parents want.
2. For inefficacious or experimental life-saving treatments: When a mature minor has a life-threatening