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ADOLESCENT COMPETENCY AND THE REFUSAL OF MEDICAL TREATMENT

Martin T. Harvey†

I. INTRODUCTION

Should adolescents₁ be allowed to refuse medical treatment such that death/serious disability will most likely be a consequence of their refusal? Tradition responds with a resounding "No." Given their minor status, adolescents have historically been lumped together with other obvious incompetents — e.g., infants — under the legal rubric of 'presumptive decisional incapacity.' As of late, while some scholars (hereafter the orthodox camp) continue to uphold a modified version of the traditional doctrine, others (hereafter the radical camp) argue for a diametrically opposed position: 'presumptive decisional capacity' for adolescents.² On the latter view, the presumptive

₁ I would like to thank my colleague Joe DeMarco for his comments and criticisms of an earlier version of this article.

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₁ By "adolescent" I mean an individual between the ages of thirteen and up to but not including eighteen years.

competency bar for both consent/refusal of medical treatment should be substantially lowered. Both types of presumptive doctrines share a common procedural virtue: each provides a fairly rigorous ‘bright line’ test to determine whether an adolescent’s decision to refuse recommended medical treatment ought to be respected. Unfortunately, however, such procedural virtues, in the present case at least, breed substantive vices. On the one hand, a doctrine of presumptive incapacity problematically excludes, as a priori incompetent, the request of a thoughtful and reflective terminally ill adolescent to forgo further clinical interventions. On the other, a doctrine of presumptive capacity problematically includes, as a priori competent, the decision of a less than reflective otherwise healthy adolescent to refuse life-saving medical treatment.

In what follows, I seek to remedy these vices by arguing for a sliding scale conception of adolescent competency pegged to the possibility of therapeutic benefit. I begin by briefly outlining the unique legal standing of adolescents. I then turn to a succinct analysis of the legal cases and principles surrounding an adolescent right to refuse medical treatment. Subsequently, I provide broad outlines of the respective arguments to be made for both presumptive capacity and presumptive incapacity of adolescent decision-making ability. At this juncture, I introduce my sliding scale approach both as a critique of, and improvement upon, the aforementioned presumptive doctrines. Lastly, I consider procedural issues entailed by my account, specifically the problem of equitable conflict resolution.

II. LEGAL BACKGROUND: ADOLESCENTS AND THE LAW

Adolescents present the law with a metaphysical quandary – their problematically crepuscular legal existence is implied in philosopher John Locke’s apt phrase that “we are born free as we are born rational; not that we actually have the exercise [at birth] of either: age that brings one brings with it the other too.” In other words,

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4 No one in the literature has yet considered a sliding scale model as a possible solution posed by the requests of adolescents to refuse medical treatment. I fully develop such a model in Section VI below.

personhood is a metaphysical process involving a transformation from becoming to being over time that at some interval, for purely practical reasons, e.g., granting the right to vote, must be rendered a legal event that, ceteris paribus, occurs at an arbitrarily fixed point in time (the age of majority). Adolescents, in many times being able to give forceful, rational articulations of their wishes and desires, are markedly different from other legal non-persons such as infants, the profoundly retarded, and the senile. Their quasi-personhood is well reflected in the law, which, observes Elizabeth S. Scott, adopts a "binary classification" scheme: occasionally adolescents count as adults but usually they count as children. On the one hand, adolescents may seek gainful employment, decide (in most states) to quit school at age sixteen, and on occasion, be held criminally responsible for their behavior. On the other, adolescents are prohibited from purchasing alcohol or cigarettes, from voting and serving on a jury, and cannot enter into binding contracts.

In the health care arena a similar 'binary classification' system exists. In the vast majority of cases physicians must (on the pain of possible battery charges) obtain parental consent before treating an adolescent. Being shy of the age of legal majority, adolescents are assumed to lack sufficient cognitive and conative maturity to craft autonomous health care choices, therefore being deemed legally incapable of giving genuine informed consent to medical treatment. The ease (and in many cases necessity) of a 'bright-line' arbitrary cutoff for such legal practices as serving on a jury, however, is not completely carried over to the domain of medical treatment. Legal exceptions, for both practical and ethical reasons, obtain. From a practical perspective, allowing adolescents an independent right to consent to some types of medical treatment, without their parents'
foreknowledge, serves important public policy goals. Thus, in the utilitarian interest of preventing suicide, curbing illicit drug and alcohol abuse and halting the spread of venereal disease, adolescents are allowed to consent to the treatment of mental health disorders, alcohol/drug addiction and STDs without parental approval. Furthermore, by and large on ethical grounds alone, abortion case law carves out an independent realm of qualified adolescent medical decision-making. In a string of related cases the courts have consistently ruled that if a minor seeking an abortion can both demonstrate the ability to understand the risks and benefits of an elective abortion procedure and provide acceptable reasons for terminating her pregnancy then she ought to be viewed as a “mature minor,” i.e., as a “child who is capable of understanding the nature and consequences of a particular medical intervention, and of its primary alternatives including non-intervention.” In turn, despite their formal minor status, such pregnant adolescents are afforded a full legal right to reproductive autonomy, substantively identical to that of their adult pregnant peers. To reason otherwise strikes many jurists as grossly iniquitous. More recently, a number of scholars have argued that sufficiently mature adolescents ought to be granted a right to consent to participate in genetic research and clinical drug trials.

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9 See, for instance, Planned Parenthood of Central Missouri v Danforth, 428 U.S. 52 (1976). See also Bellotti v Baird, 443 U.S. 622 (1979) (discussing the ability of minors to be deemed mature by courts).

10 Capron, supra note 7, at 74. Another legal avenue remains open here: the adolescent in question could be viewed as “partially emancipated” from his parents within the context of health care decision-making instead of a “mature minor” (as noted above). The latter alternative is more to the point in the context of an adolescent making an informed refusal of treatment. Emancipation normally only occurs by commissions/omissions on the part of parents, e.g., a minor becomes emancipated when his/her parents grant permission to serve in the armed forces. As such, the choice to emancipate normally rests in the parents’ hands, regardless of adolescent competency. With a ‘mature minor’ doctrine only looks to the decision-making capacities of the child in question, i.e., whether or not the minor possesses the cognitive equipment to be a “self-decider.” See id. at 72-74 (explaining that whether one is deemed a “mature minor” depends on his ability to understand his decision and its implications).

11 See, e.g., Susan E. Zinner, The Elusive Goal of Informed Consent by Adolescents, 16 THEORETICAL MED. 323 (1995) (noting that many adolescents are capable of consenting to participate in research); Robert F. Weir & Jay R. Horton, Genetic Research, Adolescents, and Informed Consent, 16 THEORETICAL MED. 347 (1995) (explaining ways to ensure that adolescents who choose to participate in genetic research are protected); Jennifer Rosato, The Ethics of Clinical Trials: A Child’s View, 28 J. OF L., MED. & ETHICS 362 (2000) (explaining the need to give mature minors more decision-making powers). These authors concur that such
III. AN ADOLESCENT RIGHT TO REFUSE LIFE-SUSTAINING MEDICAL TREATMENT: CASES AND PRINCIPLES

On which side of the binary divide would (or does) an adolescent’s right to refuse medical treatment fall? No clear-cut legal answer has been forthcoming. In what follows, I provide a brief overview of the pertinent cases and a succinct analysis of the legal principles governing the judicial decisions wrought therein. Several recent court decisions including In Re E.G. (1989), In Re Long Island Jewish Medical Center (1990) and In Re Rena (1999) govern the relevant legal topography.

(1) In Re E.G. (Ernestine Gregory). In 1989 seventeen year old E.G., of Illinois, was suffering from acute leukemia and in order to survive the medically recommended chemotherapy treatments she would need to have several blood transfusions. Her chances of long-term (>5 years) survival were estimated to be 20-25%. Both E.G. and her mother, Rosie Denton, as practicing Jehovah’s Witnesses, adamantly refused to consent to such transfusions on the grounds that they violated the basic tenets of E.G.’s religious faith. A trial judge found E.G. neglected and ordered transfusions. On appeal the appellate court found E.G. to be a “mature minor” capable of refusing blood transfusions through the exercise of her First Amendment right to freedom of religion. To substantiate its ruling, the appellate court relied on an extension of Illinois abortion provisions that allowed for a mature minor to terminate her pregnancy independently of parental consent. Nonetheless, the appellate court affirmed the neglect finding. The Illinois Supreme Court affirmed the appellate finding that E.G. was a mature minor but dismissed the neglect finding against Rosie Denton. The court reasoned that the “paramount question” before it was whether or not a minor could ever be afforded a right to refuse “life-sustaining” medical treatment. Given that E.G.’s attending physician testified that she was “competent to understand the consequences of accepting or rejecting treatment, and he [E.G.’s physician] was impressed with her maturity and the sincerity of her beliefs,” and further, that a psychiatrist claimed that E.G. had the

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12 In re E.G., 549 N.E.2d 322 (Ill. 1989).
13 Id. at 324.
14 Id. at 325.
decisional capacity of someone who was 18-21 years old, the court found that a right to refuse medical treatment, on the basis of such “clear and convincing evidence,” could be exercised by a mature minor like E.G.\(^5\) Nonetheless, this right was not absolute; it could be limited by the state interest to preserve life, the doctrine of \textit{parens patriae} (particularly in light of the long-term prognosis), and the interest of relevant third parties, i.e., the minor’s parents and guardians. Crucially, the hypothetical objection of Ms. Denton against her daughter’s refusal would have “weighed heavily” against the ascription of a right to refuse medical treatment to E.G., regardless of her maturity.\(^6\)

(2) \textit{In Re Long Island Jewish Medical Center}.

In 1990, seventeen-year-old Phillip Malcolm, of New York, was suffering from widespread metastatic cancer and in order to survive recommended chemotherapy treatments a series of blood transfusions were deemed essential. Given prompt commitment to chemotherapy, the chances of short term (up to two years) remission of Mr. Malcolm’s cancer was estimated to 75\% with long term survival pegged at 25-30\%. As a practicing Jehovah’s Witness, Mr. Malcolm, with parental support, refused consent for the necessary transfusions. The Supreme Court of New York ruled against Mr. Malcolm primarily because he failed to show clear and convincing evidence that he was capable of making such a mature, reflective and weighty decision, e.g. he knew little of the Jehovah Witness faith other than the prohibition on blood transfusions and described himself as a “child” to the court.\(^7\) Nonetheless, Justice Posner recommended that the state “take a hard look at the ‘mature minor’ doctrine and make it either statutory or decisional law in New York.”\(^8\)

(3) \textit{In Re Rena}.\(^9\) In 1999, seventeen-year-old Rena (not her real name), of Massachusetts, suffered a lacerated spleen in a snowboarding accident and required a blood transfusion to survive. With the transfusion her long-term health prospects were excellent. Rena, however, was a practicing Jehovah’s Witness, and with her parents support, refused to consent to a blood transfusion. A court ordered transfusion was approved. On appeal and following \textit{In Re E.G.}, the appellate court severely chastised the trial judge for refusing to consider whether or not Rena was a mature minor. As Rena had

\(^{15}\) \textit{id.} at 323-24, 327.

\(^{16}\) \textit{id.} at 328.


\(^{18}\) \textit{See id.} at 241-43 (holding that the patient was not a “mature minor”).

\(^{19}\) \textit{id.} at 243.

checked out of the hospital on the day following the transfusion and was no longer in medical danger the case was vacated on mootness grounds.

In turn, four legal principles come to bear on the decisions of the court in the aforementioned cases:

(1) An unqualified liberty interest possessed by competent adults to refuse any and all medical treatments even if the consequences are fatal.\textsuperscript{21}
(2) A qualified liberty interest possessed by parents to make medical decisions for their minor children.\textsuperscript{22}
(3) A state interest, as exemplified in the doctrine of *parens patriae*, in protecting incompetents from their own bad decisions and the bad decisions of those trusted to care for them.\textsuperscript{23}
(4) A state interest in the preservation of life.\textsuperscript{24}

Clearly, (1) is the most important governing principle listed above.\textsuperscript{25} In line with Cardoza's famous dictum, it is by now judicially well established that every person of "adult years and sound mind" has the right to determine what happens to their own bodies.\textsuperscript{26} The motivating ethical idea thereby captured, of course, is that adults of

\textsuperscript{21} See Bouvia v Superior Court, 225 Cal. Rptr. 297, 300-01 (App. Div. 1986) (holding that competent individuals have a right to refuse medical treatment); *In re Farrell*, 529 A.2d 404 (1987) (holding the right of an adult to refuse life saving treatment); and *Cruzan v Director, Missouri Dept. of Health*, 497 U.S. 261, 262 (1990) ("A competent person has a liberty interest . . . in refusing unwanted medical treatment"). For succinct commentary see LEANNA DARVALL, *MEDICINE, LAW AND SOCIAL CHANGE* 54-84 (1993).

\textsuperscript{22} See Wisconsin v. Yoder, 406 U.S. 205 (1972) (discussing parents' right to refuse compulsory formal education for their children) and Parham v. J.R., 442 U.S. 584, 602, (1979) (discussing the family unit and the role of parents to act in the best interests of their children).

\textsuperscript{23} See *In re Hamilton*, 657 S.W.2d 425, 429 (Tenn. Ct. App. 1983) (upholding the doctrine of *parens patriae* in action ordering parents to get medical treatment for their twelve year old daughter).

\textsuperscript{24} See *In re Conroy*, 486 A.2d 1209, 1233 (N.J. 1985) (noting the commonly held belief that states may act to preserve life) and *Cruzan*, 497 U.S. at 280-81 (holding that Missouri's interest in protecting and preserving human life was legitimate).

\textsuperscript{25} Two other state interests, preventing suicide and maintaining the ethical integrity of the medical profession, are often cited — see Superintendent of Belchertown State School v. Saikewicz, 370 N.E.2d 417, 425 (Mass. 1977) — but are assigned no weight in the typical adolescent refusal of treatment case. *In re E.G.*, 549 N.E.2d at 328.

\textsuperscript{26} Schloendorff v. Soc'y of N.Y. Hosp., 105 N.E. 92, 93 (N.Y. 1914).
sound mind are autonomous beings whose choices, including whether or not to consent to medical treatment, ought to be respected. The factual question, aside from having reached the age of majority (to which I return momentarily) is whether or not a particular individual is competent, i.e., retains adequate decisional capacity. Succinctly, competency implies the presence of a decision-making process that reflects the workings of an autonomous mind. Importantly, the standard of competency to which adults are held in order to exercise a right to refuse medical treatment is exceedingly low. So long as they apparently understand the risks and consequences of their prospective choice to refuse, regardless of how irrational such a choice may strike their attending physicians, patients are protected by principle (1) from any outside interference. Adults are thus presumed competent, i.e., their choices are respected so long as they do not display any overt delusional behavior. The legal onus is on the health care team to provide clear and convincing evidence to the contrary. For competent adults principle (1) conclusively trumps all of the other principles combined.

What is the relevant upshot here? Specifically, a ‘mature minor’ doctrine that allows for the ascription of a right to refuse medical treatment to a particular adolescent essentially, for all legal intents and purposes, effects a qualified transformation of that minor individual into a de facto adult who now falls, at least in great part, under the rubric of principle (1). An adolescent, such as E.G. or Rena, who has been declared a mature minor in this context deserves to have her preferences and desires given tremendous weight, bordering on those of a legal adult. She should not be precluded from “possessing and exercising certain rights normally associated with adulthood.”

Importantly, however, and unlike someone who has reached the age of majority, an adolescent such as E.G. must meet a “clear and convincing” evidence standard before being afforded such a change in her legal status. The onus is thus on her to prove competency by evidencing her capacity to provide a through understanding of the consequences of her proposed decision to terminate treatment along with well articulated reasons as to why her decision ought to be respected. Following In Re Long Island Jewish Medical Center, adolescents who fail to measure up to such a demanding standard will be denied a right to refuse medical treatment. The courts have thus primarily adopted an evidentiary approach to adolescent competency;

27 In re E.G., 549 N.E.2d at 325.
28 Id. at 327.
29 557 N.Y.S.2d at 243.
it constitutes the *exception*, not the norm. Furthermore, even if an adolescent meets these evidentiary requirements, her right to refuse, unlike that of a competent adult, is by no means absolute — her decision to refuse treatment *may*, but need not, be trumped by principles (2)-(4).

Principle (2) has long been recognized as being embodied in the common law. Given their presumably deep feelings for the welfare of their children, parents are allowed a great deal of liberty in choosing appropriate medical care for them. This state of affairs is well recognized in the law whereby, as noted above, medical practitioners who fail to obtain the informed consent of parents before performing procedures on their children can possibly be held liable for battery. Parents are also provided with relatively wide latitude to refuse treatment, again on the assumption that they have the best interests of their children at heart. As such, in the cases above, parental support is given great weight, particularly in *In Re E.G.*, for allowing the exercise of a right to refuse life-sustaining medical treatment by an adolescent — even if said adolescent satisfied the mature minor criterion. The tremendous weight attached to parental support should come as no surprise in the above cases as the attempted exercise of a right to refuse was being made on religious grounds, another area traditionally under parental purview. To allow the easy exercise of such a right on such grounds, absent parental input and support, was deemed too potentially harmful to legitimate third party, i.e. parental, interests.

Principle (2) itself, as well as the mature minor qualified version of principle (1), may be limited by principle (3), the traditional *parens patriae* interest that the state has in protecting incompetents, particularly minor children, from irrational and dangerous decisions whether attempted to be made on their behalf by their parents/guardians or by themselves. As Justice Posner observes in *In Re Long Island Jewish Medical Center*, “parents may throw their own lives away if they wish, but they cannot make martyrs of their children.” Presumably then, as in the case of Philip Malcolm, if an adolescent is incapable of understanding the tenets of his or her religious faith, then *regardless* of his or her parents’ support, he or she cannot be allowed to refused treatment on such grounds. Also, as Justice Ryan, writing for the majority in *E.G.*, notes “where the health care issues are potentially life threatening, the State *parens patriae* interest is greater than if the health care matter is less

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30 *Id.*
Thus, the state apparently has a duty to weigh well any attempted exercise of a right to refuse life-sustaining treatment by a minor – mature or otherwise. One would also expect this state interest to be weighted even heavier if the procedure in question would restore the adolescent to (near) complete health. As such, principle (3) depending upon the circumstances, can trump principles (1) and (2) either taken singly or combined. Lastly, and normally cited either prior to, or on the heels of, principle (3) is principle (4), the state interest in the preservation of life. Clearly, our judicial tradition has always recognized this principle as being of the ‘core’ variety. Prima facie, the state views the life of any citizen, unless conclusive evidence is presented to the contrary, such as a competent adult exercising a right to refuse medical treatment, as worthy of preservation and protection. Hence, principle (4) is particularly relevant in cases when “a minor’s life and health are at stake . . . [particularly if said] minor may have a long and fruitful life ahead.”

Principle (4), normally but not necessarily in combination with principle (3), can also be weighted heavily enough to override both principles (1), at least in the case of mature minors, and (2).

The current legal landscape could thus be summarized as follows: In jurisdictions where mature minor doctrines are recognized, adolescents who produce clear and convincing evidence satisfying the criteria thereof have been afforded a qualified liberty interest (unlike competent adults whose liberty interest thereunto is unqualified) to forgo further life-sustaining treatment. Their right to forgo such treatment, however, has been tempered both by the third party interest of their parents to choose the medical care they believe most appropriate for their minor children and the state’s interest in the preservation of life. Furthermore, the courts have ruled that both the liberty interests of the minor’s themselves and their parents may be trumped by the state doctrine of parens patriae. Nonetheless, the principles discussed above have been applied to a very idiosyncratic set of cases: each involved an adolescent Jehovah’s Witness who wished to refuse treatment for religious reasons. What about the refusal of treatment by a minor in the case of terminal/chronic illness simply on the grounds that they wish to forgo further suffering?

Consider the 1994 cases of Benny Agrelo and Billy Best. Benny Agrelo was a fifteen-year old living in Florida who had undergone

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31 In re E.G., 549 N.E.2d at 327.
32 Id.
33 See Christine Gorman, A Sick Boy Says “Enough!”, TIME, June 27, 1994, at 65 (noting how adverse side effects led Benny to give up treatment).
two liver transplants. Due to severely debilitating side effects experienced while taking the immunosuppressant drug cyclosporin, Benny decided to stop taking his medication thereby potentially inducing liver failure. He was briefly forced to resume his immunosuppressant regimen by the Florida Department of Health and Rehabilitative services. A Broward County juvenile court judge decided, after lengthy separate meetings with Benny, his mother (who was initially opposed to her son’s refusal), and Benny’s health care team, that Benny was mature enough to understand what he was doing. The judge subsequently permitted Benny to make his own decision and prohibited further interference from either the state of Benny’s physicians. After a few months without immunosuppressants, Benny died of liver failure. Unfortunately, since juvenile court records are sealed, we cannot learn the judge’s precise reasoning but presumably he decided the case along similar jurisprudential lines as E.G., i.e., Benny understood the consequences of his decision, was suffering from a severe chronic illness and had the eventual support of his mother.

Billy Best presents perhaps an even more provocative case. As a sixteen-year old living in Massachusetts, Billy was diagnosed with Hodgkin’s disease. With a full course of chemotherapy treatments Billy’s physicians predicted a 90% chance of a cure. Two months into his six-month chemotherapy regimen Billy rebelled against further treatment, claiming that the medications were “killing him.” Fearing that further chemotherapy sessions would be forced, Billy ran away from home. After subsequent promises from his parents not to force treatment Billy returned to New England (where he continues to live) and began alternative therapies. The state chose not to intervene. Should Billy’s decision have been allowed to stand? Clearly, given the high chance of a cure, it would seem that the state could have exercised its interests both in the preservation of life and on the grounds of parens patriae. Was Billy really competent to make such a decision, even with the agreement of his parents? Scholars are deeply divided on this issue. On the one hand, what might be termed the ‘radical’ camp argues for presumptive decisional capacity for adolescents. As such, the autonomy bar for medical decision-making would be substantively lowered to include almost all adolescents. On the other, the ‘orthodox’ camp, as it were, views such a move with deep suspicion and either claims that competency alone is insufficient

35 Id.
to grant such a powerful liberty interest, or that the notion of a ‘mature minor’ itself is substantively bankrupt. Adolescents thus should not be afforded an independent autonomy right to refuse medical treatment. In the next section I briefly summarize and critique each position.

**IV. ARGUMENTS FOR RADICAL AND ORTHODOX CONCEPTIONS OF ADOLESCENT AUTONOMY**

The radical conception of adolescent autonomy has a great deal of *prima facie* ethical force: only competence matters. As Sarah Elliston vociferously contends “there is something inherently unjust about the concept of adults, who function at similar reasoning levels as adolescents, possessing additional rights merely as a function of chronological age.”

Such ‘treat equals equally’ sentiments certainly have some merit seeing as they are deeply woven into the historical fabric of Anglo-American jurisprudence. After all, as several scholars have pointed out, it appears hypocritical at best to allow a juvenile to be tried as an adult, and indeed even be sentenced to death, yet at the same time, to prohibit this very same juvenile from having any genuine input into the course of their medical treatment.

Similar to Elliston, Rhonda Gay Hartman has argued in two recent articles that, as part of a broader program to carve out a separate constitutional realm for adolescents, the traditional doctrine of presumptive decisional incapacity is an affront to the “dignity” of the vast majority of adolescents who are quite capable of deciding for themselves whether or not to undergo a recommended medical intervention.

She contends that the ethically suspect and practically inconsistent notion of presumed decisional incapacity must be replaced by the concept of “autonomous decisional ability” on the part of adolescents. On her view (as well as Elliston’s), unless they prove otherwise by their overt behavior, adolescents, simply as a class, ought to be presumed competent to refuse medical treatment. In turn, the clear and convincing evidence standard and evidentiary approach to adolescent competency as set down in E.G. is simply too restrictive. Instead, the following regulative ideal should obtain: adolescents should simply be viewed as on par, autonomy-wise, with their

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37 See, e.g., Hartman, *supra* note 2, at 1267, 1287 (noting the incongruity of treatment of adolescents).
38 See id. at 1321 (describing a situation where treatment prolongs suffering with a low therapeutic value).
39 Id. at 1270-71. See also Hartman (2001), *supra* note 2, at 87-88.
chronologically advanced peers. The onus should thus be on physicians to prove incompetency as opposed to burdening adolescents, as is now the case in even the most liberal of jurisdictions, with proving that they are competent. To add empirical meat to their radical proposal, these scholars reference numerous social psychological studies, the most famous of which was conducted by Weithom and Cambell (1982), which provide evidence of the comparable decision-making capacities of adults and adolescents with regard to consenting/refusing to medical treatment. In sum, on this view Billy Best, Rena, Benny Agrello, E.G., and potentially even Philip Malcolm (who did understand that refusing transfusions would hasten his death) would be presumed competent and should be afforded an autonomy right to refuse further medical interventions.

In arguing that 'competency is competency regardless of age' the position crafted by proponents of the radical view is both provocative and powerful. Nonetheless, when pushed, I believe that a fatal weakness becomes exposed. Consider the following hypothetical:

Upon visiting a cardiologist after suffering from a severely irregular heart beat, a seventeen-year-old high school football player is informed that he needs surgery to correct a potentially fatal heart valve defect. Once performed, he will be able to resume most daily activities and should live out his normal lifespan. Unfortunately, however, as a complication of surgery he will no longer be able to play football. The teen claims that football is the most important thing in his life and that he would rather die than give up the game he loves. He adamantly opposes surgery, while readily admitting that he understands that the consequences of his decision would most likely prove fatal.

L.A. Weithom & S.B. Cambell, The Competency of Children and Adolescents to Make Informed Treatment Decisions, 53 CHILD DEVELOPMENT 1589-98 (1982). They found that fourteen-year-olds, on average, were just as competent to understand the risks and benefits of various hypothetical treatment interventions, as well as able to provide an acceptable reason for their choice, as the eighteen- and twenty-one-year-old 'adult' control groups. In turn, nine-year-olds tested at a significant 'competency-disadvantage'. The results of their study, however, must be taken with a grain of salt: all participants were healthy and all participants were from white, well educated, upper-middle class, North American families. Given the demographic narrowness of the representative sample it would seem hazardous, from a policy implementation perspective, to generalize the study into supporting the notion of presumptive competency for all adolescents' fourteen-years of age and up.

This case is a version of an example employed by James F. Drane, The Many Faces of Competency, 15(2) THE HASTINGS CENTER REPORT, April 1985, at 17,
Should this adolescent’s decision be allowed to stand – even with parental support? Most physicians, lawyers and adolescent psychologists would be appalled if it were. Indeed, both the state’s interest in the preservation of life and the doctrine of *parens patriae* could, in the present legal climate, be readily invoked to override the youth’s decision – with or without parental support. And presumably with good reason. Nonetheless, on the radical view summarized above, it is hard to see why the teen’s decision to refuse treatment should *not* be respected. After all, he is not delusional, e.g., he does not believe that his heart valve defect will miraculously disappear, and furthermore, he is making a choice consistent with what he values most in life, football. If he were eighteen clearly his choice would have to be respected. Most of us would find such a choice as decidedly irrational and tragic, i.e., ‘a waste of a life’, but nonetheless in a liberal society such as ours who is to say that one’s dominant conception of the good life *cannot* be active participation in football. Hartman (who unfortunately does not consider such hard cases) claims that *parens patriae* remains “foundational” but goes on to argue that the concept needs to be revolutionized in the case of adolescents as a vehicle for the promotion of “self-determination” as opposed its traditional role of preventing adolescents from making an irrational refusal. As such it would seem that from a legal and public policy perspective, the radical view, in this very important instance, leaves much to be desired.

On the opposite end of the spectrum, the orthodox view avoids such concerns but as I argue below it falls victim to an equally problematic objection. Proponents of the orthodox view normally adopt one of two strategies: either they cast serious dispersions on the decisional capacities of adolescents or they grant that adolescents are competent but that parental support functions as a necessary condition for any adolescent refusal of treatment. Either way, the resulting conception of adolescent competency is severely constrained. With regards to the first strategy, many scholars argue that the radical camp’s reliance on a presumptive decisional capacity standard for adolescents is empirically flawed. Substantive differences

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purportedly exist between the respective healthcare decisional capacities of adolescents and adults. Specifically, as noted by Ann Driggs, adolescents, unlike adults, tend to be much more likely to make decisions based upon a desire for peer acceptance, many times discount long term costs in favor of short term benefits, and display, on average, a much greater willingness to make risky choices.\(^4\) “Age-relative values” thus potentially cloud the adolescent’s ability to render a rational decision in line with their long-term best interests.\(^5\) Such tendencies are further exacerbated by what Jennifer Penkower refers to as the “uniqueness of the chronically ill adolescent.”\(^6\) To wit, chronically ill adolescents, e.g., teen age renal transplant recipients, usually experience severe isolation and loneliness due to their difficulty of forming lasting peer relationships, frustration at the thought of a potentially bleak future, excessive dependence upon their parents (particularly when their peers are becoming increasingly independent) and typically exhibit dangerously low levels of compliance to life sustaining treatment regimens. As such, chronically ill adolescents are much more likely to suffer from severe depression thereby leaving it open to serious doubt as to whether a request for the refusal of further treatment is prompted by serious and thoughtful reflection or underlying mental illness. Such behavior on the part of chronically ill adolescents “markedly exceeds that of similarly ill adults.”\(^7\) Based upon such dour empirical assessments, presumptive decisional incapacity to refuse treatment constitutes the most prudent default position.


6 Ladd and Forman distinguish between “age-specific values” and, by implication, “age-independent values”: the former tend to change as one matures while the latter, once obtained, remain constant. For adolescents, age-specific values include such things as high emphases on “body image” and “acceptance by peer group.” Clearly, these values can seriously impede one’s capacity to make a competent decision, e.g., refusing chemotherapy for a cancer with a high cure rate simply due to fear of temporary hair loss. The authors, in the context of consent to participate in genetic research, argue that, at times, adults should allow adolescents to decide on the basis of such values. Their article does not address (nor was it meant to) the issue of an adolescent right to refuse life-prolonging treatment in the case of terminal illness. They borrow their version of the distinction from Michael Slote, Goods and Virtues (1983).

7 Penkower, supra note 43, at 1194.

4\(^{2}\) Id. at 1208.
Another tack pursued by members of the orthodox camp, as put forth by Lainie Friedman Ross, is to recognize that some adolescents are competent to make such choices but their competency at best counts as a necessary, and never a sufficient, condition for the refusal of medical treatment.\(^4\) Ross places great weight on principle (2) above; namely that parents have a fundamental right to make medical decisions for their children.\(^4\)\(^9\) This right, in turn, should only be trumped on the strictest grounds of state sanctioned parens patriae. Succinctly, for Ross, an adolescent, regardless of competence, ought never be afforded an independent right to refuse medical treatment. She bases her claim on two arguments: first, citing empirical evidence in line with her orthodox bedfellows, Ross contends that parents ought to have the right to restrict the competent minor’s short term freedom to refuse medical interventions in favor of promoting his or her “lifetime autonomy.”\(^5\)\(^0\) That is, as the custodians of their children’s potential to enjoy a freedom-filled future life parents may, at their discretion, decide that medical treatment for a recalcitrant competent child is necessary even if it contravenes the latter’s wishes. Second, Ross further argues that families qua families are ethically integrated decisional units that exhibit a species of autonomy in their own right.\(^5\)\(^1\) Succinctly, the interests of the family do not necessarily reduce to the interests of the individual members. Therefore, as guardians of the family’s autonomy as well, parents may trump a competent child’s wish to refuse medical treatment on the grounds that it threatens the integrity of the family unit. To sum up, on either of the orthodox views (which tend to be mutually re-enforcing) none of the adolescents mentioned in the above cases would have been afforded an independent right to refuse medical treatment – at best, and following particularly Ross, this right resides with their parents. Legal interest should thus focus on principles (2), (3) and (4) when approaching cases involving an adolescent request to refuse medical treatment. Attempts to promote presumptive adolescent capacity through the extension of principle (1) to cover most cases of adolescent refusals of treatment should be resisted for both empirical and ethical reasons (as noted).

Consider, however, the diametrically opposed instantiation of the erstwhile adolescent football worshiper discussed above:

\(^{48}\) Ross, supra note 2, at 56-74.
\(^{49}\) Id. at 135-37.
\(^{50}\) Id. at 61.
\(^{51}\) Id. at 62.
A sixteen year old is suffering from terminal leukemia. His disease has progressed to the point where he is no longer a suitable candidate for bone marrow transplantation. A combination of chemotherapy and radiation treatment was temporarily successful but recently the cancer has metastasized to several major organs. Additional radiation treatments may prolong the teen’s life for up to three months. The teen himself declares that he has suffered enough and wants all treatment to stop. His anguished parents disagree and demand that ‘everything be done.’

To force treatment under such circumstances strikes most people completely unreasonable. So long as the adolescent understands the consequences of his decision and can provide a minimally rational reason for so choosing (e.g., ‘I’ve suffered enough’) why not afford him an identical legal status to a similarly situated terminally ill adult? In such cases, the state interests in the preservation of life and even parens patriae wane considerably. Regardless of age, the decision to forego life prolonging treatment by a terminally ill, suffering individual ought to be viewed as prima facie rational and the individual crafting such a choice as ought to be viewed prima facie competent. Such decisions, if made by those in their legal majority, would not be construed as peer pressured, short sighted or overly risky. What about them being made by an adolescent entails the contrary? Concerns over the promotion of future ‘life autonomy’ appear decidedly to miss the point. Indeed, the refusal of life prolonging medical interventions may be the only chance that the terminally ill teen ever has to exercise the type of ‘life-autonomous’ choice that most of us so unreflectively take for granted. Unfortunately, the orthodox camp tends to gloss over such cases (Ross for instance never considers such a possibility) much to its detriment.\textsuperscript{52} Given these inadequacies of both the radical and the orthodox camps in the next section I explore a middle path that hopefully avoids the vices, but retains the virtues, of each.

\textbf{V. A SLIDING SCALE APPROACH}

What is the best method for determining adolescent competency to refuse medical treatment? Following James Drane’s influential article, I want to argue for a modified version of the “sliding-scale”

\textsuperscript{52} \textit{Id.} at 133-42 (the author only discusses parental refusals in the case of terminal illness).
conception of competency.\footnote{Drane, supra note 41, at 18-20. Rosato, supra note 2, at 61-65 for instance, relies on a static conception in proffering her account. See also Driggs, supra note 43, at 715-17, aptly articulating her concluding worries about granting adolescents a right to die, unfortunately does not consider a sliding scale approach.} As noted at the outset, conceiving of competency in a sliding scale fashion assesses the possession thereof as a matter of requisite degree proportionate to the possibility of therapeutic benefit. Drane rejects the traditional "all or nothing approach" to competency as either too exclusive, i.e., too many people are prevented from exercising their right to medical self-determination or too inclusive, i.e., too many people are permitted to make egregiously unsound medical decisions.\footnote{Id.} A sliding scale perchance avoids these errors by, on the one hand, setting an extremely low threshold of competence to refuse medical treatment where little prospect for therapeutic benefit obtains, while on the other, ratcheting up the degree of competency required to refuse medical treatment as expected therapeutic benefit increases accordingly. Importantly, outcome, i.e., expected therapeutic benefit, here functions as a limiting condition on a right to treatment refusal as opposed to the ground thereof. In other words, failure to take probable outcome into account, particularly when the stakes are extremely high, e.g., when refusing a potentially life-saving intervention, indicates a serious flaw in an individual’s medical decision-making process. In turn, the evidentiary requirements so created range from the mere ability to engage in evincing a choice to the much more complex decisional capacity of displaying sustained critical reflection by providing recognizably sound reasons for treatment refusal. In the case of legal adults, if adopted, Drane’s proposal would effect a tremendous normative transformation of the relevant legal topography by, on one end of the spectrum, raising the competency bar to a much higher level than it is today. For instance, a Jehovah’s Witness, on Drane’s scheme, might well be prohibited from refusing a life-sustaining blood transfusion unless he or she could articulate, in considerable detail, the credos of his or her faith. Given the haunting specter of increased paternalism many scholars have rejected Drane’s proposal out of hand.\footnote{See Jessica Wilen Berg et al., Constructing Competence: Formulating Standards of Legal Competence to Make Medical Decisions, 48 Rutgers L. Rev. 345, 378, 388, 396 (1996) (discussing the need to examine policy implications before creating a standardized determination of competency).} 

Strictly limited to adolescents, however, Drane’s approach appears to resolve the ethical conundrum sketched above: it sets very
low standards for refusing medical treatment in the case of terminal illness but prohibits such refusals as the potential for therapeutic benefit increases accordingly. *A priori* presumptive schemes give way to an *a posteriori* assessment of each individual’s unique medical circumstances. Adopting a sliding scale approach to adolescent competency thus gels nicely with the desire to proceed on a case-by-case basis. In doing so, I believe that the employment of a sliding-scale escapes the pitfall of over-inclusiveness that plagues the radical alternative while simultaneously eluding the trap of over-exclusiveness entailed by the orthodox view. Specifically, a sliding scale would prevent an adolescent from ‘throwing’ his or her life away if the prospect of a cure were great, while it would not force a terminally ill adolescent to undergo further treatment that simply prolongs life in the short term with no prospect of therapeutic benefit. It thus squares quite well with our gut level intuitions as to when paternalistic interventions are justified in the case of adolescents and when they are not. Succinctly, a sliding scale approach to competency pegs the degree of competency expected of someone to refuse medical treatment to reflect the degree of risk involved in making that decision, i.e., the riskier the decision, the higher the standard of competency required. Adolescent patients held to the highest standard, i.e., attempting to refuse treatment where the prospect of therapeutic benefit is tremendous, would in effect be barred from forgoing such interventions. Following E.G., refusals in cases of moderate therapeutic benefit would require the adolescent to possess an intimate understanding of the life threatening consequences of refusing medical treatment and that he or she be able to provide clearly articulated reasons consistent with stated values as to why their decision to refuse treatment ought to be respected. Lastly, adolescent patients held to the lower standard would simply have to be aware that they were terminally ill and exhibit sufficient capacity to refuse further interventions by appeal to minimally acceptable reasons, e.g., ‘I’ve suffered enough.’

The following table provides a general schema of the practical implications of adopting the sliding scale approach. I subsequently expand upon successive pairs of bold face categories in turn.

*Table 1: A Sliding Scale Approach to Assessing Adolescent Competency to Refuse Medical Treatment*
### A. Therapeutic Benefit and the Nature of Intervention

'High' therapeutic benefit means that both the patient’s short- and long-term prognoses are excellent. A near full recovery from whatever malady afflicts them is expected and they should, other things being equal, live out their normal life span unaffected by their present medical problem. Such interventions ought to be characterized as ‘Life-Saving.’ ‘Moderate’ therapeutic benefit means that the long-term prognosis is decidedly problematic but that in the short term an intervention may well provide the patient with a few additional years of life. Nonetheless, the patient can expect little improvement in overall quality of life for any substantial length of time as well as a negative impact on ‘normal’ adolescent life activities such as participation in sports or attending school on a regular basis. Over the long term, death will most likely result from their present medical condition. Such interventions ought to be characterized as ‘Life-Sustaining.’ ‘Low’ therapeutic benefit means that both the patient’s short- and long-term prognoses are extremely poor. The patient will most likely die in a matter of months, there being no therapeutic

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56 By ‘moderate therapeutic benefit’ I mean that a medical intervention is likely to produce a short term (2-3 years) life extension but the long term (>5 years) outlook remains quite bleak
adolescents left in the medical arsenal. Such interventions ought to be characterized as ‘Life-Prolonging’.

B. Acceptable Reasons for Refusal and the Category of Decisional Capacity: On the one hand, in the case of ‘Life-Saving’ medical interventions no acceptable reasons proffered by an adolescent to refuse medical treatment pass muster: empirical studies cited by proponents of the orthodox camp should here give great pause. In these instances, ‘presumptive decisional incapacity’ ought to be the norm. On the other, reasons for refusal of treatment by terminally ill adolescents ought to be at most ‘minimally rational.’ If these individuals understand that their condition is terminal, i.e., that further interventions will be devoid of therapeutic benefit, and if they refuse further medical interventions on universally acceptable grounds, i.e., the desire to avoid future suffering, etc., then the adolescent’s choice should be respected. In these situations, ‘presumptive decisional capacity’ should be the norm. Where therapeutic benefit is moderate, as defined, the adolescent seeking to refuse further treatment ought to be held to a very high standard of competency, i.e., he or she must provide clear and convincing evidence of their competency to refuse. Reasons for refusal must be reflective, clearly articulated, and consistent with a well-developed set of values concerning what makes life worth living and why continued medical treatment would sabotage such worth — i.e., such reasons must be ‘maximally rational.’ For instance, among other things, an adolescent Jehovah’s Witness falling into this category would have to demonstrate a thorough knowledge of her faith before being allowed to refuse a life sustaining blood transfusion. Here an ‘evidentiary’ case by case approach needs to be adopted with regards to decisional capacity to insure that sufficient capacity obtains to make such weighty decisions. Even though the long-term prognosis may be bleak, as in the case of chronic renal disease, the possibility of several years of additional life merits a much deeper plumbing of the adolescent’s reasons to refuse than in cases where the prospect of therapeutic benefit is low.

C. Parental Support: Clearly, most parents have an integral, and legally recognized, interest in the medical welfare and future well being of their children. As such they retain a great deal of decision-making authority thereunto. Nonetheless, as discussed above, the state, on the grounds of parens patriae may usurp this decision-making authority if the parents appear intent upon making a poor medical choice for their children. Hence, even if parents would support their minor child’s decision to refuse life-saving medical treatment such support is tout court insufficient. In the case of ‘life-sustaining’ medical treatment, however, the situation changes:
parental support is necessary for any adolescent right to refuse treatment. Here Ross's concerns about the family as an ethically integrated unit and the state's duty to protect legitimate third party interests come to the fore. To permit children to refuse life saving or even life-sustaining treatment contrary to their parents' wishes, for example, on religious grounds, would irreparably harm the legitimate third party interest that parents have in the potential medical decisions crafted by their minor children. In the case of 'terminal illness', however, given that the prospect of therapeutic benefit is nil, it is hard to imagine what legitimate third party interest would be served by forcing treatment. In such instances, parental support for the adolescents' right should be unnecessary so long as the adolescent in question exhibits the minimal degree of competency discussed above.

D. Right to Refuse: Given that there are no acceptable reasons to refuse life saving treatment on the part of adolescents, regardless of apparent capacity or parental support, no right is afforded them to do so. Adolescents who wish to refuse life-sustaining treatment, however, may be extended a 'weak' right in this regard; i.e., the permissibility of their refusal is contingent upon clear and convincing proof of competency and parental support. Lastly, terminally ill adolescents, so long as they satisfy minimal conditions of competency ought to be afforded a 'strong' right to refuse further medical treatment, independent of parental support.

E. Case Classification. High Therapeutic Benefit: As noted, in instances where high therapeutic benefit is at stake, adolescents are simply prohibited from refusing treatment. In this instance, any liberty interest that the youth in question might have is trumped both by the legitimate third party interests of their parents to decide appropriate medical treatment for their minor children and state interests in the preservation of life, and if necessary, parens patriae. Hence, the adolescent football player who would rather perish than give up the game he loves would not be permitted to forgo the necessary valve replacement surgery. Likewise, both Billy Best and Rena would be overruled - regardless of parental support and the maturity of their attendant decisional capacities. Why? In Mr. Best's case, Hodgkin's lymphoma is an eminently treatable form of cancer with a cure rate, so long as aggressive therapy is immediately instituted, in excess of 80%. Although he may believe that he is currently alive in spite of his two (out of a recommended six) months of chemotherapy, it is much more likely that he is alive because of the aggressive treatment of his oncology team. What if Mr. Best had refused all treatment to begin with? Should his decision still be allowed to stand? Clearly, there is no principled way to demarcate between the refusal to initiate highly successful treatment (except for
the rather lame plea: 'Try it and see if you like it') and the refusal to continue with such treatment only one-third of the way through its recommended course. To sanction Mr. Best's refusal of treatment creates a slope so slippery that no state or third party interest could possibly be invoked to trump an adolescent decision to refuse any treatment – regardless of therapeutic benefit. Rena presents a similar situation: clearly a lacerated spleen is life threatening but with surgery and sufficient blood transfusions a complete recovery is (and proved to be) possible. Regardless of parental support, and contra the appellate court's commentary, Rena's maturity and commitment to her religious faith in such a situation ought to be beside the point.

Why the a priori bar to an adolescent right to refuse a 'life-saving' medical intervention? Many adolescents might well satisfy the competency criterion established for similarly situated adults. Pace Elliston, why prohibit their treatment refusals? Here we would agree with Ross: it is essential for both parents and society to protect the future lifetime autonomy of adolescents.\(^{57}\) The minimal competency standard adopted in the case of adult refusals of lifesaving medical treatment simply reflects the priority we assign to liberty in our society. Adults may drink excessively, chain-smoke, ride motorcycles (in some states without helmets), and engage in a host of other extremely risky behaviors, not because there is a difference in kind per se between the decisional capacities of adults and adolescents, but rather due to the priority of value placed upon individual liberty in our society. To permit adults to make such irrational and foolish decisions is a necessary cost of our Millian commitment to broad individual freedom concerning personal behavior and lifestyle choice. Such a state of affairs, however, does not entail that we cannot provide future "emergent" persons of our society with a protective cocoon in which to shelter them from the bad and foolish decisions that they might otherwise make.\(^{58}\) Furthermore, given that the empirical evidence cited by proponents of the orthodox camp casts at least some doubt on the capacity of adolescents to craft health care decisions unsullied by peer pressure and myopic perceptions of risk, it would seem particularly prudent in cases of high therapeutic benefit treatment refusal to error on the side of caution.

**Moderate Therapeutic Benefit:** To paraphrase the majority decision in *In Re E.G.*, the state's *parens patriae* interests fades both with increasing maturity and diminished possibility of therapeutic

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\(^{57}\) Ross, *supra* note 2, at 61.

\(^{58}\) *Id.* at 61. See also Capron, *supra* note 7, at 89 (stating that society has an interest in protecting those who do not have the ability to protect themselves).
benefit. On a sliding scale approach E.G., Philip Malcolm and Benny Agrelo all fall into this category and ought, so long as they pass muster, to be afforded a weak right to refuse further treatment. None are by definition terminally ill as each retains better than even chances of living several more years should treatment be initiated/continued. The state therefore has the right to demand clear and convincing evidence that the minor involved be sufficiently mature, i.e., exhibit the requisite degree of capacity, to refuse further treatment – the state interest in the preservation of life, though correspondingly weak, still brings sufficient residual force to bear. Unlike adults, the court may, and ought, to ‘quiz’ the minor individual to insure that the stated reasons for refusal are clear, consistent and reflective of a deeper set of values. The burden of proof rests on the minor in question. E.G. and Benny Agrelo measured up to such a rigorous standard while Philip Malcolm did not – hence the former, in conjunction with parental support, would be allowed by the sliding-scale, should they so desire, to refuse further life sustaining treatment.

**Low Therapeutic Benefit:** On the sliding scale model, in the case of terminal illness the state’s *parens patriae* interests diminish to near non-existence, as does the state interest in the preservation of life. Third party interests in continued non-therapeutic treatment also border on being completely de-legitimized. In the scenario of the terminally ill adolescent leukemia patient the burden of proof now shifts to the health care team if the youth’s competency is to be called into question. Why extend essentially *a priori* presumptive decisional capacities to terminally ill adolescents? Here we agree with Hartman.\(^5^9\) Indeed, to force treatment in such situations inevitably begs the question that simply ‘being alive’, as opposed to ‘having a life’ in the deepest narrative sense, is a worthwhile state of affairs in its own right. This is particularly so if the life to be lived amounts to little more than a few additional pain-stricken weeks or months of bedridden existence. Little if any reason readily presents itself to hold such egregiously ill adolescents to a demanding standard of competency. Presumably, in such circumstances, they are well and truly the best judges of their own good. Given the tragic nature of the illness and the likelihood that death is relatively imminent, the state interest in the preservation of life would seemingly not apply and the exercise of *parens patriae* is only warranted if the patient were completely delusional. What of parents’ third-party interest to consent/refuse medical treatment for their minor children? Given the

\(^5^9\) Hartman, *supra* note 2, at 1321. *See also* Rosato, *supra* note 2, at 72-74 (discussing the state interest in preserving life).
adolescent’s dire medical circumstances and that further therapeutic intervention will be devoid of benefit, the adolescent’s liberty interest in refusing treatment ought to be allowed to outweigh all other interests that would force treatment to continue – even those of his or her parents. Hence, in these cases adolescents ought to be afforded a strong right to refuse medical treatment, a right no different in substance from that of similarly situated terminally ill adults; potential problems posed by peer pressure and shortsightedness would appear to lose much of their negative force.

F. Empirical Studies. On a final brief note, a sliding scale model also gels nicely with the well-conducted empirical studies presented by both the radical and the orthodox camps. On the one hand, Driggs’s and others’ research concerning the corrosive effects of peer pressure, shortsightedness, and heightened willingness to render risky, i.e., foolish, healthcare choices support the prohibition on adolescent treatment refusal in the case of life-saving medical interventions. On the other, the empirical work cited by Hartman and Elliston would certainly appear to provide an experiential basis for the ascription of a strong right of treatment refusal to terminally ill adolescents. Lastly, given that neither set of studies carry enough empirical weight to shift the balance decidedly in favor of one camp at the expense of another, an evidentiary, case-by-case approach appears to be well warranted in cases such as Benny Agrelo or Philip Malcolm.

VI. PROCEDURAL ISSUES: PRACTICAL APPLICABILITY AND CONFLICT RESOLUTION

So proffered, the sliding scale model provides a great deal of policy guidance: it affords a prima facie ‘bright line’ test at either end of the therapeutic spectrum but also recognizes that when the stakes are neither high nor low an evidentiary approach emerges as the most appropriate policy option to balance the more equally weighted legal and ethical interests. In opposition to its thoroughly bright-line brethren, hopefully a sliding scale approach, to steal a phrase from H.L.A. Hart, successfully resists imposing “uniformity at the price of distortion.” Nonetheless, given the number of parties and interests involved, conflicts are sure to arise. For a sliding scale conception to be practically applicable proper procedures must be imposed to resolve such conflicts with minimal harm to the interests of all affected individuals.

The easiest sorts of potential conflicts to dispense with involve the attempt by an adolescent to refuse life-saving treatment – with or without parental support. As noted, all such requests should be overridden since the minor in question is so bereft of a liberty interest
in this context that the situation borders on there being no conflict of interests at all. Attempts to refuse life-sustaining treatment present slightly more complicated procedural difficulties. Here, a conflict is likely to arise between the parents and minor child on one side and the health care team on the other. By and large, when dealing with such scenarios the current status quo should be retained. Normally, in the present legal milieu, such cases result in the health care team seeking a court order authorizing continued treatment and the parents and adolescent petitioning that no such order be granted. In an emergency situation, the default policy should be to continue treatment. Once the patient's medical condition has stabilized a full psychiatric work-up would be in order as well as meetings of the health care team and the parents, and hopefully the adolescent, with a trial court judge in order for the court to determine whether or not the clear and convincing evidence burden has been met. Such a process is most likely to be quite cumbersome, but given the absence of any acceptable bright line indicators it appears to be the only viable option. A further difficulty might arise if, as in E.G., the minor in question is too ill to attend a court proceeding. In such circumstances a general modification is in order: why not employ real time video conferencing technology that would allow the judge to engage the patient in an in-depth conversation to determine if the requisite degree of decisional capacity obtains? Otherwise, the potential right to refuse, its present weakness notwithstanding, inevitably risks being held hostage to contingent medical circumstance.

The thorniest procedural issue, however, remains: what about a conflict between an apparently competent terminally ill adolescent and his or her parents concerning non-therapeutic treatment continuation? Undoubtedly, such a situation is tragic for all parties involved, and it is especially difficult for the attending physician. Following Hartman, legislative action that carves out a precisely specified, independent realm of adolescent decision-making strictly limited to Low Therapeutic Benefit scenarios constitutes the best solution.60 The current conservative political climate, however, bodes ill for such a sweeping proposal. Pursuing a piecemeal approach appears as the only politically palatable option. Even so, an adolescent liberty interest can be established and protected – particularly if hospital protocols and physician backing are forthcoming. Where do physicians stand on this issue? Although data are scanty, as evidenced in a recent survey conducted by Hartman,

60 My opposition to Hartman would be with the extent of such a realm as opposed to its existence.
two-thirds of physicians queried on this matter responded by saying
that, if forced, they would support the terminally ill adolescent against
his or her parents — in court if necessary. 61

Going to court, however, should be an “eleventh-hour” maneuver.
A more incremental approach proves critical. Obviously, the
regulative ideal in such cases is that the parents allow the adolescent
to decide as he or she sees fit, implicitly recognizing, as it were, their
competent minor child’s de facto liberty interest. Except in the most
extreme circumstances, this ideal can still be closely approximated,
even if an initial conflict erupts. To defuse a parental-adolescent
clash, a second physician, unconnected with the case, should be called
in to confirm the terminal diagnosis. A psychiatric consult should
also be performed to insure that the teen is neither delusional nor so
depressed as to be incapacitated — again, following the sliding-scale
model the onus must be on the psychiatrist to prove incapacity. At
this juncture, a meeting with the parents, the adolescent, the attending,
the psychiatrist and a social worker should be held to present reports
on both the capacity assessment (presumably positive) and the
diagnostic findings to the parents. An attempt should be made to
convince the reluctant parents, that given the absence of therapeutic
benefit, their child is quite capable of deciding for him- or herself,
whether further interventions are warranted. Efforts to secure the
support of the parents for the adolescent’s decision to refuse treatment
are essential.

If the parents continue to insist on treatment then the hospital
ethics committee should be alerted and presumably come out in
support of the patient. At this juncture, a patient advocate should also
be made available to the adolescent and, if all other options fail, a
court order should be sought permitting the patient to exercise his or
her right to refuse further medical treatment. As noted above, if the
patient is too ill to attend court then real time video conferencing
equipment should enable the judge to make a relatively pro forma
competency evaluation — particularly since the requisite degree of
competency involved is minimal at most. Upon the affirmative
findings of the court, the adolescent would be free to exercise his or
her protected liberty interest to refuse non-therapeutic interventions.
A final attempt at reconciliation ought to be undertaken but in the
event of failure the third party interest in forcing continued treatment
is simply too weak to override the adolescent’s liberty interest to the
contrary.

61 Hartman (2001), supra note 2, at 110-12.