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ADVANCING THE RIGHTS OF CHILDREN AND ADOLESCENTS TO BE ALTRUISTIC: BONE MARROW DONATION BY MINORS¹

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I. INTRODUCTION

It's sort of fun to save someone's life—it's not an everyday chance.

—nine year old bone marrow donor

A donor made this statement the day after a bone marrow harvest and transplant and appears to be a fairly typical sentiment of minor donors.⁵ Bone marrow transplants from siblings are often the last and best chance to save the lives of children and adolescents with leukemia and a variety of other serious diseases. However, the legal basis for allowing minors to donate bone marrow to their brothers and sisters, a procedure that entails some risk to the donor, has not been satisfactorily articulated. Most courts faced with the question have relied on the best interests of the child standard to ground the authorization of these transplants and have, therefore, required a showing that the donation was in the donor's best interest. These courts have emphasized the psychological benefit that redounds to the minor donor who participates in the procedure and potentially saves the life of his or her sibling.

However, a pure best interests standard does not fully capture the nature of the decision to donate bone marrow, nor does it incorporate a respect for persons that would protect the rights and dignity of the donor child. This article examines the standards used for answering the question of whether minors should be allowed to donate bone marrow. Part II introduces the legal background and the standards currently used by courts. Part III explores the unsatisfactory nature of these standards. Part IV presents an empirical study that is intended to provide some help in understanding what might be a useful

⁵Interview with nine year-old bone marrow donor in Minneapolis, MN (February 1994).

and respectful standard. Part V concludes the article with a discussion of two alternative revised standards grounded in the doctrines of substituted judgment and the best interests of the child.

II. BACKGROUND

A. Bone Marrow Harvests from Minors

Bone marrow transplants can often mean the difference between life and death for children and adolescents with leukemia and other childhood cancers, aplastic anemia, and immune deficiency diseases.⁶ Because the bone marrow for the transplant comes from another human being, one who is healthy, there are important ethical issues to consider. One area of particular interest is whether minors should be allowed or required to donate bone marrow to their critically ill siblings.⁷ The closer the tissue match is between the donor and the recipient, the better are the chances of a successful transplant because genetic similarity reduces the likelihood that the recipient's immune system will reject the transplanted tissue or that the recipient will suffer from graft versus host disease.⁸ Therefore, biological siblings of the sick child are often the best source of tissue to transplant.

This raises the question of whether a healthy child or adolescent should be allowed or required to undergo a bodily invasion that is not physically beneficial to him or her in order to possibly save the life of a sibling.⁹ The law has long protected against unwanted violations of the body. This is evidenced by the statement that "[n]o right is held more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference

⁶Bone marrow transplantation has become an increasingly used treatment for pediatric cancers over the last decade. Approximately 2,000 U.S. children and adolescents undergo a bone marrow transplant each year for pediatric cancers, aplastic anemia, and metabolic disorders. S.K. STEWART, *BONE MARROW TRANSPLANTS: A BOOK OF BASICS FOR PATIENTS* 67 (1992).

⁷See generally Victoria Weisz, *Psycholegal Issues in Sibling Bone Marrow Donation*, 2 *ETHICS & BEHAV.* 185, 189 (1992).

⁸Charles H. Baron et al., *Live Organ and Tissue Transplants from Minor Donors in Massachusetts*, 55 B.U.L. REV. 159, 159 (1975). Graft v. host disease occurs when the donor bone marrow recognizes the recipient as a foreign environment and can cause rash, jaundice, diarrhea, and death. AMERICAN MEDICAL ASS'N, *ENCYCLOPEDIA OF MEDICINE* 195 (Charles B. Clayman ed., 1989).

⁹The procedure is typically performed while the donor is under general anesthesia. Three to five percent (one or two pints) of the donor's bone marrow is removed with a long hollow needle from several locations on the pelvic bone. The marrow is processed and is then transplanted into the recipient whose own bone marrow has been destroyed with drugs and/or radiation to allow for the transplanted bone marrow. The donor's bone marrow replenishes itself within a few weeks. ROBERTA ALTMAN & MICHAEL SARG, *THE CANCER DICTIONARY* 32-35 (1992).

of others, unless by clear and unquestionable authority of law."¹⁰ Accordingly, at least one court has upheld the power of a competent adult to refuse to participate in a transplant as a donor,¹¹ and other courts have refused to disclose the names of potential donors without their consent.¹² In refusing to require an adult to donate bone marrow to his cousin even though such refusal meant that the cousin would die, the court in *McFall v. Shimp* said:

The common law has consistently held to a rule which provides that one human being is under no legal compulsion to give aid or to take action to save another human being or to rescue. . . . For our law to *compel* defendant to submit to an intrusion of his body would change every concept and principle upon which our society is founded. To do so would defeat the sanctity of the individual, and would impose a rule which would know no limits, and one could not imagine where the line would be drawn.¹³

In contrast, minors are not usually held to be legally competent to give or to withhold consent.¹⁴ Instead, parents have traditionally been able to consent to therapeutic medical treatment for their children.¹⁵ A bone marrow harvest, however, is not medically beneficial to the donor and, in fact, places that child at some risk and in some discomfort.¹⁶ Although parents are normally assumed to act in their children's best interests, the ability of the parents to act in the best interests of the prospective donor when faced with the possible death of the

¹⁰Union Pac. Ry. Co. v. Botsford, 141 U.S. 250, 251 (1891) (refusing to require a plaintiff to submit to a medical examination to ascertain the extent of her injuries without her consent).

¹¹McFall v. Shimp, 10 Pa. D.&C.3d 90 (Allegheny County Ct. 1978).

¹²See *Head v. Colloton*, 331 N.W.2d 870 (Iowa 1983) (upholding hospital refusal to disclose name of unrelated match who had indicated unwillingness to donate except for family members); *In re George*, 625 S.W.2d 151 (Mo. 1982) (refusing to open adoption records to provide sick individual with name of natural father who was unwilling to be a donor).

¹³McFall, 10 Pa. D.&C.3d at 91 (emphasis added).

¹⁴RESTATEMENT (SECOND) OF TORTS § 892A (1979). The doctrine of informed consent requires that consent to health care be intelligent, knowing, and voluntary. This doctrine supports the ideal that the patient and physician together will determine the appropriate course of treatment. ALLEN E. BUCHANAN & DAN W. BROCK, *DECIDING FOR OTHERS: THE ETHICS OF SURROGATE DECISION MAKING* 224 (1990).

¹⁵Linda S. Ewald, *Medical Decision Making for Children: An Analysis of Competing Interests*, 25 ST. LOUIS U. L.J. 689, 691 (1982).

¹⁶Baron et al., *supra* note 8, at 163 n.20. The physical risks include the risks attendant to general anesthesia; slight risk of bone fracture, bone infection, or rupture of an artery; and the possibility of skin scarring. *Id.* Psychological risks include the fear of operations, fear of losing a body part, and the psychological harm that can result if the recipient dies. *Id.*

sick sibling has been questioned.¹⁷ For example, the court in *Curran v. Bosze* acknowledged the concern on the part of hospital officials that "the parent had both a sick child and a healthy child, and in their desire for the sick child to get better, they might . . . overlook the potential risks to the healthy child."¹⁸

*Bonner v. Moran*¹⁹ has been cited as authority for the principle that a parent may consent to non-therapeutic medical procedures for a child.²⁰ In that case, a doctor was held liable for assault and battery for removing skin from a fifteen-year-old boy to graft to his cousin without the consent of the boy's parents.²¹ However, as one commentator pointed out, the facts of the case required only that the court hold that parental consent was *necessary* and did not rule on whether or not parental consent would be *sufficient* to authorize a non-therapeutic medical procedure on a minor.²² Similarly, in *Zaman v. Schultz*, the court held a doctor liable for taking blood from a minor to transfuse to another patient without the donor's parents' consent, but did not expressly hold that such consent would have been sufficient.²³

While the Supreme Court has demonstrated in several contexts an unwillingness to intervene in the decisions of parents regarding their children,²⁴ the Court has also recognized that there are limits to parental authority: "Parents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they

¹⁷*Id.* at 160; Thomas H. Murphy, Jr., *Minor Donor Consent to Transplant Surgery: A Review of the Law*, 62 MARQ. L. REV. 149, 152 (1978).

¹⁸566 N.E.2d 1319, 1337 (Ill. 1990).

¹⁹126 F.2d 121 (D.C. Cir. 1941).

²⁰*Hart v. Brown*, 289 A.2d 386, 390 (Conn. Super Ct. 1972); Ewald, *supra* note 15, at 691.

²¹*Bonner*, 126 F.2d at 122.

²²Rodney K. Adams, *Live Organ Donors and Informed Consent: A Difficult Minuet*, 8 J. OF LEGAL MED. 555, 577 (1987).

²³19 Pa. D.&C. 309 (Cambria County Ct. 1933).

²⁴*See, e.g., Wisconsin v. Yoder*, 406 U.S. 205 (1972) (holding that the 1st and 14th Amendments prevented the state from compelling respondents (Amish) to send their children to formal high school until the age of 16); *Pierce v. Society of Sisters*, 268 U.S. 510, 534-35 (1925) (upholding an injunction against enforcement of a state statute that required parents to send children between the ages of 8 and 16 to public school stating that the statute "unreasonably interferes with the liberty of parents and guardians to direct the upbringing and education of children under their control"); and *Meyer v. Nebraska*, 262 U.S. 390 (1923) (holding that the 14th Amendment precluded states from prohibiting the teaching of foreign languages to children in schools violated the 14th Amendment).

can make that choice for themselves."²⁵ Thus, it is unclear whether a parent may give legal consent for their child to undergo a bone marrow harvest in order to benefit a sibling.

B. Standards Used by Courts

Many of these cases, in which minors are called upon to donate tissue to their siblings, do not go to court, being resolved instead through hospital administrative procedures. This reflects an understanding on some level that parental authority is sufficient to authorize the harvest. However, there is also a body of case law that has attempted to address these questions. Courts facing this dilemma²⁶ have relied on the mature minor doctrine,²⁷ the substituted judgement standard,²⁸ the best interests of the child standard,²⁹ or a review of the fairness and reasonableness of the parental decision.³⁰

1. Mature Minor Doctrine

Some minors possess the maturity and intellect to express their wishes, to exercise responsible judgment, and to make complex decisions.³¹ The law has recognized this through the mature minor doctrine. Many states have promulgated statutes that allow minors, on a finding a sufficient maturity, to give legally effective consent to some types of medical treatment. A number of statutes condition the provision of legally effective consent by minors on attainment of a specific age (ranging between twelve and seventeen years old)

²⁵*Prince v. Massachusetts*, 321 U.S. 158, 170 (1944) (upholding a state statute prohibiting minors from selling in the streets in the context of distribution of religious literature).

²⁶Courts have been confronted with these questions in the contexts of kidney and blood donations as well as bone marrow harvests and in situations where the prospective donor is either mentally incompetent or incompetent due to minority. The issues in these cases will be treated as the same unless otherwise stated.

²⁷*Rappeport v. Stott*, Civil No. J 74-57 (Mass. Aug. 28, 1974) (discussed in Baron et al., *supra* note 8).

²⁸*Strunk v. Strunk*, 445 S.W.2d 145 (Ky. 1969).

²⁹*Curran*, 566 N.E.2d at 1322; *In re Richardson*, 284 So.2d 185 (La. Ct. App. 1973); *In re Doe*, 481 N.Y.S.2d 932 (N.Y. App. Div. 1984); *Little v. Little*, 576 S.W.2d 493 (Tex. Civ. App. 1979); *In re Pescinski*, 226 N.W.2d 180 (Wis. 1975).

³⁰*Hart v. Brown*, 289 A.2d 386 (Conn. Super. Ct. 1972); *Nathan v. Farinelli*, Eq. No. 74-87 (Mass. July 3, 1974) (discussed in Baron et al., *supra* note 8).

³¹See, e.g., Thomas Grisso & Linda Vierling, *Minors' Consent to Treatment: A Developmental Perspective*, 9 PROF. PSYCHOL. 412 (1978); David G. Scherer, *The Capacities of Minors to Exercise Voluntariness in Medical Treatment Decisions*, 15 LAW & HUM. BEHAV. 431 (1991); David G. Scherer & N. Dickon Reppucci, *Adolescents' Capacities to Provide Voluntary Informed Consent: The Effects of Parental Influence and Medical Dilemmas*, 12 LAW & HUM. BEHAV. 123 (1988); Lois A. Weithorn & Susan B. Campbell, *The Competency of Children and Adolescents to Make Informed Treatment Decisions*, 53 CHILD DEV. 1589 (1982).

and/or limit the specific treatments for which such consent is deemed adequate.³²

Some commentators have suggested that the mature minor doctrine does not apply to the organ and tissue donation context because the procedure is not physically therapeutic for the donor.³³ These commentators would limit minors' ability to give legal consent to those cases in which the treatment or procedure is physically beneficial to the minor. However, at least one court has allowed a seventeen year-old minor to donate bone marrow based solely on the fact that he was capable of legal consent.³⁴ Based in part on a psychiatrist's opinion that the donor "should be allowed to make his own independent decision about any matters affecting his welfare," the court held that the donor was "capable of consenting to the proposed procedure so as to prevent the creation of liability therefor."³⁵ Moreover, several states have enacted statutes that specifically allow some minors to give legally effective consent to a bone marrow harvest.³⁶ It has been suggested that, perhaps, a two-tiered structure

³² See, e.g., ALA. CODE § 22-8-4 to -6 (1990) (authorizing minors fourteen-years-old or older to give consent to any medical treatment and any minor to give consent to treatment related to pregnancy, sexually transmitted diseases, and chemical dependency); CAL. FAMILY CODE § 6920 - 6929 (West 1994) (authorizing minors fifteen-years-old and older to consent to most medical treatment and minors twelve-years-old and older to consent to some mental health treatment, treatment for substance abuse, and diagnosis and treatment of rape and of communicable diseases); HAW. REV. STAT. § 577A -1 to -2 (1985) (authorizing all minors to give consent for treatment related to pregnancy, sexually transmitted diseases, and family planning); ME. REV. STAT. ANN. tit. 32, § 3292 (West Supp. 1994) (authorizing any minor to give consent for treatment of sexually transmitted diseases and substance abuse); MD. CODE ANN., HEALTH-GEN. § 20-101-104 (1990 & 1994 Supp.) (authorizing minors seventeen-years-old and older to give consent for treatment of substance abuse, sexually transmitted diseases, pregnancy, contraception, and rape exams and authorizing minors sixteen-years-old and older to consent to treatment of mental or emotional problems). Most states also have provisions allowing minors to give legally effective consent if they are married or otherwise emancipated from their parents. See OKLA. STAT. tit. 63, § 2601 - 2602 (West 1984 & 1995 Supp.) for a typical example.

³³ Ewald, *supra* note 15, at 703-04 ("often an adolescent minor has the intelligence and maturity to understand the nature and consequence of the proposed treatment and is thereby capable of consenting to *beneficial* treatment") (emphasis added); ANGELA RODDEY HOLDER, LEGAL ISSUES IN PEDIATRICS AND ADOLESCENT MEDICINE 134 (2d ed. 1985).

³⁴ Rappeport, Civil No. J 74-57 (discussed in Baron et al., *supra* note 8, at 176).

³⁵ *Id.*

³⁶ See, e.g., ALA. CODE § 22-8-9 (1990); WIS. STAT. ANN. § 146.34. (West 1989). The Alabama statute provides:

Any minor who is 14 years of age or older, or has graduated from high school, or is married, or having been married is divorced or is pregnant, may give effective consent to the donation of his or her bone marrow for the purpose of bone marrow transplantation. A parent or legal guardian may consent to such bone marrow donation on behalf of any other minor. Ala. Code § 22-8-9 (1990).

The Wisconsin statute is more detailed. In relevant part, it provides:

(3) Consent to donation of bone marrow by a minor under 12 years of age. If the medical condition of a brother or sister of a minor who is under 12 years of age requires that the brother or sister receive a bone marrow transplant, the minor is deemed to have given consent to be a donor if all of the following conditions are met:

(a) The physician who will remove the bone marrow from the minor has informed the parent, guardian or legal custodian of the minor of all of the following:

1. The nature of the bone marrow transplant.
2. The benefits and risks to the prospective donor and prospective recipient of performance of the bone marrow transplant.

3. The availability of procedures alternative to performance of a bone marrow transplant.

(b) The physician of the brother or sister of the minor has determined all of the following, has confirmed those determinations through consultation with and under recommendation from a physician other than the physician under par. (a) and has provided the determinations of the parent, guardian or legal custodian under par. (e):

1. That the minor is the most acceptable donor who is available.
2. That no medically preferable alternatives to a bone marrow transplant exist for the brother or sister.

(c) A physician other than a physician under par. (a) or (b) has determined the following and has provided the determinations to the parent, guardian or legal custodian under par. (e):

1. The minor is physically able to withstand removal of bone marrow.

2. The medical risks of removing the bone marrow from the minor and the long-term medical risks for the minor are minimal.

(d) A psychiatrist or psychologist has evaluated the psychological status of the minor, has determined that no significant psychological risks to the minor exist if bone marrow is removed from the minor and has provided that determination to the parent, guardian or legal custodian under par. (e).

(e) The parent, guardian or legal custodian, upon receipt of the information and the determinations under pars. (a) to (d), has given written consent to donation by the minor of the bone marrow.

(4) Consent to donation of bone marrow by a minor 12 years of age or over. (a) A minor who has attained the age of 12 years may, if the medical condition of a brother or sister of the minor requires that the brother or sister receive a bone marrow transplant, give written consent to be a donor if:

1. A psychiatrist or psychologist has evaluated the intellect and psychological status of the minor and has determined that the minor is capable of consenting.

2. The physician who will remove the bone marrow from the minor has first informed the minor of all of the following
 - a. The nature of the bone marrow transplant.
 - b. The benefits and risks to the prospective donor and prospective recipient of performance of the bone marrow transplant.

- c. The availability of procedures alternative to performance of a bone marrow transplant.

(b) If the psychiatrist or psychologist has determined under par. (a) that the minor is incapable of consenting, consent to donation of bone marrow must be obtained under the procedures under sub. (3).

might be used, with courts requiring "a higher level of competency to consent to nontherapeutic procedures than is ordinarily required for therapeutic procedures."³⁷

2. Substituted Judgment Standard

The substituted judgment standard originated to allow a surrogate decision-maker to distribute an incompetent's property for the support of his relatives by considering what the incompetent would do were he or she competent.³⁸ Over the years, evidentiary requirements, such as evidence of previous giving or of statements regarding intentions to give, were introduced to increase the persuasiveness of the notion that the court could determine what the incompetent person would do if he or she were competent.³⁹ More recently, substituted judgment has been used in the medical decision-making context in cases that consider decisions at the end of life.⁴⁰

Using a subjective form of substituted judgment, courts attempt to determine what the incompetent person would have chosen, if competent, based on his or her behavior and statements made in a prior period of competency. Thus, the decision of a third party (e.g., the court or a family member), advised by information about the incompetent person's wishes, values, and goals, is substituted for the decision of the incompetent person. When executing a decision based on the substituted judgment standard, a court purports to "determine and effectuate, insofar as possible, the decision that the patient would have made if competent. Ideally, both aspects of the patient's right to bodily integrity - the right to consent to medical intervention and the right to refuse it - should be respected."⁴¹ In this way, the state affords respect for individuals and protects "the same panoply of rights and choices it recognizes in competent persons."⁴²

³⁷Adams, *supra* note 22, at 577. Such a two-tiered structure has been suggested by Buchanan and Brock in the different, but similar, context of consenting to versus refusing therapeutic treatment.

[T]he fact that a child is competent to consent to a treatment does not imply that he or she is competent to refuse it *and vice versa*. For example, consent to a low-risk, life-saving procedure by an otherwise healthy child should require a minimal level of competence, while refusal of that same procedure by the child should require the very highest level of competence. BUCHANAN & BROCK, *supra* note 14, at 239-40.

³⁸*Ex parte* Whitbread, 35 Eng. Rep. 878 (1816).

³⁹Louise Harmon, *Falling Off the Vine: Legal Fictions and the Doctrine of Substituted Judgment*, 100 YALE L.J. 1, 24-29 (1990).

⁴⁰*See, e.g., In re* Quinlan, 355 A.2d 647 (N.J. 1976).

⁴¹*In re* Conroy, 486 A.2d 1209, 1229 (N.J. 1985).

⁴²*Superintendent of Belchertown State School v. Saikewicz*, 370 N.E.2d 417, 428 (Mass. 1977).

Thus, in the context of a prospective minor bone marrow donor, this standard would require the parent or the court to assess the minor's feelings, values, and goals and to determine what the minor would have chosen if he or she were competent. For example, in *Strunk v. Strunk*, the court, in authorizing a kidney transplant from an incompetent person, Jerry, to his brother, examined Jerry's reactions and values.⁴³ The court noted the identification Jerry felt with his brother, the importance to him of his brother's visits, the important role the brother played in his improvement, Jerry's awareness that he played a role in the relief of the family's tension, and the possibility of Jerry's guilt if his brother were to die. Holding that the doctrine of substituted judgment was "broad enough not only to cover property but also to cover all matters touching on the well-being of the ward," the court held that it had the power to authorize the transplant and that the transplant would further Jerry's interests.⁴⁴

3. Best Interests of the Child Standard

Some courts and commentators have argued that the substituted judgment approach is not appropriate in the pediatric bone marrow transplantation context as, by definition, minors have had no prior experience in legal decision-making. The determination of what the minor would do if competent is, therefore, thought to be too uncertain to justify putting the minor at risk.⁴⁵ Alternately, these courts consider what course of action is in the best interest of the minor. An early expression of the best interests standard stated the goal succinctly: "Above all things, the paramount consideration is, what will promote the welfare of the child?"⁴⁶

Because it is clear that acting as a bone marrow donor is not medically therapeutic, the donation is not in the physical best interests of the donor sibling. Thus, courts look to evidence of the psychological impact on the minor of donating versus not donating in determining whether the harvest would be in the donor's best interest. The best interest standard in this context turns on whether the psychological outcome of the donation will be positive and, if so, whether such a beneficial psychological result outweighs any physical risks.⁴⁷

⁴³445 S.W.2d at 146-48.

⁴⁴*Id.*

⁴⁵*Curran*, 566 N.E.2d at 1326; David S. Lockemeyer, *At What Cost Will the Court Impose a Duty to Preserve the Life of a Child?* 39 CLEV. ST. L. REV. 577, 586 (1991).

⁴⁶*Chapsky v. Wood*, 40 Am. Rep. 321 (1881).

⁴⁷To date, no studies have been completed that directly assess the question of psychological benefits to minor bone marrow donors. Weisz, *supra* note 7, at 189. One study has addressed the reactions of unrelated bone marrow donors to the death of the recipient. The findings indicate that unrelated donors rarely experience guilt following the death, but often experience fairly intense feelings of grief. However, this study used a sample of adult, unrelated donors and its generalizability to child or adolescent siblings is questionable. V.A. Butterworth et al., *When Altruism Fails: Reactions of Unrelated Bone Marrow Donors When the Recipient Dies*, 26 OMEGA 161 (1992-93).

Some of the factors considered include: the quality and importance of the relationship between the prospective donor and the recipient;⁴⁸ the physical risks of the harvest to the prospective donor;⁴⁹ the distress of the family;⁵⁰ the support available to the donor;⁵¹ the potential guilt should the child not donate or should the child donate and the recipient die anyway;⁵² the recipient's prognosis with and without the transplant;⁵³ the availability of other medically appropriate options;⁵⁴ and the prospective donor's degree of understanding of the situation and awareness of his or her role.⁵⁵

One factor that a court might consider is whether the donor is likely to derive psychosocial benefits from being a bone marrow donor. Fellner and Marshall studied adult kidney donors and found that the psychosocial consequences of donating included increased self-esteem, growth as a person, and satisfaction in the recovery of the recipient, as well as an identification of the experience as one of the most meaningful in the donor's life.⁵⁶ Bernstein and Simmons studied kidney donors, including a small sample of adolescents, and found that the donors experienced gratitude from the recipient and the rest of the family and felt personally rewarded because they had saved another's life. In addition, they found that the adolescents experienced increases in self-esteem that were even greater than those experienced by a comparison group of adults.⁵⁷ Freund and Siegel commented on the special closeness that characterizes the relationship between many bone marrow donors and their sibling recipients following the transplant.⁵⁸

⁴⁸ See, e.g., *Hart*, 289 A.2d at 389; *Curran*, 566 N.E.2d at 1343; *Strunk*, 445 S.W.2d at 146; *Little* 576 S.W.2d at 498.

⁴⁹ See, e.g., *Hart*, 289 A.2d at 389; *Curran*, 566 N.E.2d at 1337; *Strunk*, 445 S.W.2d at 148-49; *Little*, 576 S.W.2d at 499.

⁵⁰ See, e.g., *Hart*, 289 A.2d at 389.

⁵¹ See, e.g., *Curran*, 566 N.E.2d at 1335.

⁵² See, e.g., *Curran*, 566 N.E.2d at 1335; *Strunk*, 445 S.W.2d at 147.

⁵³ See, e.g., *Hart*, 289 A.2d at 388; *Curran*, 566 N.E.2d at 1333; *Strunk*, 445 S.W.2d at 147; *In re Richardson*, 284 So. 2d at 187; *Little*, 576 S.W.2d at 499.

⁵⁴ See, e.g., *Hart*, 289 A.2d at 388; *Strunk*, 445 S.W.2d at 146; *In re Richardson*, 284 So. 2d at 187; *Little*, 576 S.W.2d at 497; *In re Pescinski*, 226 N.W.2d at 181.

⁵⁵ See, e.g., *Hart*, 289 A.2d at 389; *Curran*, 566 N.E.2d at 1334; *Strunk*, 445 S.W.2d at 146; *Little*, 576 S.W.2d at 498.

⁵⁶ Carl H. Fellner & John R. Marshall, *Kidney Donors Revisited*, in ALTRUISM AND HELPING BEHAVIOR 351 (J.P. Rushton & R.M. Sorrentino eds., 1981); Carl H. Fellner & John R. Marshall, *Kidney Donors: The Myth of Informed Consent*, 126 AM. J. PSYCHIATRY 1245 (1970).

⁵⁷ Dorothy M. Bernstein & Roberta G. Simmons, *The Adolescent Kidney Donor: The Right to Give*, 131 AM. J. PSYCHIATRY 1338 (1974).

⁵⁸ Barbara L. Freund & Karolynn Siegel, *Problems in Transition Following Bone Marrow Transplantation: Psychosocial Aspects*, 56 AM. J. ORTHOPSYCHIATRY 244 (1986).

Some courts have embraced psychological testimony regarding the impact of the options surrounding organ or tissue donation and have used it as a basis for authorizing the harvest:

I am satisfied from the testimony of the psychiatrist that grave emotional impact may be visited upon Leonard [prospective donor] if the defendants refuse to perform this operation and Leon [prospective recipient] should die, as apparently he will. Such emotional disturbance could well affect the health and future well-being of Leonard for the remainder of his life. I therefore find that this operation is *necessary* for the continued good health and future well-being of Leonard and that in performing the operation the defendants are conferring a benefit upon Leonard as well as upon Leon.⁵⁹

Other courts have declined to authorize transplants after finding that no benefit to the donor had been established.⁶⁰

4. Fairness and Reasonableness of the Parental Decision

Some courts have elected to conduct a review of the parental decision, in which the court objectively examines the parents' motivation and reasoning in reaching the decision to consent to the harvest.⁶¹ This method of review recognizes the parents' "right and responsibility" to make the decision while concurrently allowing the court to monitor the decision to ensure that the parents, who have a conflict of interest, will give due consideration to the risks faced by the healthy child.⁶² In doing so, the court weighs the interests of both children and the family to ensure that the decision made by the parents is "fair

⁵⁹Madsen v. Harrison Eq., No. 68651 (Eq. Mass. Sup. Jud. Ct. June 12, 1957) (emphasis added). See also *In re Doe*, 481 N.Y.S.2d at 932; Little, 576 S.W.2d at 493.

⁶⁰*Curran*, 566 N.E.2d at 1319 (declining to authorize a bone marrow transplant because the evidence supported the guardian *ad litem's* recommendation that "it is not in the best interest of either Allison or James to undergo the proposed bone marrow harvesting procedure"); *In re Richardson*, 284 So. 2d at 185 (finding that the "surgical intrusions and loss of a kidney clearly would be against Roy's best interest"); *In re Pescinski*, 226 N.W.2d at 180 ("In the absence of real consent on his part, and in a situation where no benefit to him has been established" the court refused to authorize a kidney transplant). These are the only identified reported cases in which the court did not authorize the transplant. In these cases, the courts found that there were factors which may have mitigated against the harvest. In *Richardson*, the parents of the incompetent prospective donor were in disagreement over whether the harvest should take place; in *Pescinski* a competent brother of the recipient refused to be tested for compatibility; and in *Curran* the mother of the prospective donors would not consent to their acting as donors (in fact, would not consent to their even being tested) for their half-brother.

⁶¹Hart, 289 A.2d at 386; *Nathan*, No. 74-87 (discussed in Baron et al., *supra* note 8).

⁶²Baron et al., *supra* note 8, at 171-76.

and reasonable."⁶³ Thus, reviewing the parental decision involves, at least in part, an assessment of the best interests of the prospective minor donor.

In reviewing the fairness and reasonableness of the parental decision, one court considered the testimony of a clergyperson indicating that "the decision by the parents of the donor and donee was morally and ethically sound" and the testimony of the parents which revealed that they had only been able to make the decision "after many hours of agonizing consideration."⁶⁴ The court concluded that parents ought to be able to consent to organ donation "when their motivation and reasoning are favorably reviewed by a community representation which includes a court of equity" and, accordingly, the court authorized the transplant.⁶⁵

III. STANDARDS NOT ENTIRELY SATISFACTORY

Courts have used each of these standards to resolve cases involving organ and tissue donations by minors. However, each of these standards has proven to be limited in the extent to which it can provide the legal basis for these decisions. While the mature minor standard is substantively acceptable, it is so narrow in scope as not to apply in most cases. Conversely, the other doctrines (best interests, substituted judgment, and the fairness and reasonableness of parental decisions), while potentially applicable to a wide range of cases, are substantively problematic.

A. Mature Minor Standard

The mature minor approach provides those minors who are sufficiently mature and intelligent with the opportunity to make a variety of their own health care decisions. This doctrine allows minors to attempt to rebut the law's presumption of their incompetence by showing that their decision-making abilities are developed enough that they should be found competent to decide for themselves on a particular question.⁶⁶ However, this doctrine only applies to a small percentage of minor bone marrow donors. Many mature minor statutes only allow minors above a certain age (ranging from 12 to 17) to make their own decisions and some require a finding of sufficient maturity.⁶⁷ In addition, many statutes authorize minors to give legally effective consent only in specific health care contexts such as pregnancy or substance abuse.⁶⁸ These requirements combine to severely limit the instances in which minors can consent to bone marrow harvests under these statutes. Moreover, if a two-tiered

⁶³*Id.*

⁶⁴*Hart*, 289 A.2d at 389-90.

⁶⁵*Id.* at 391.

⁶⁶BUCHANAN & BROCK, *supra* note 14, at 225.

⁶⁷*See generally supra* note 31.

⁶⁸*Id.*

standard is applied, requiring an even greater level of maturity to consent to nontherapeutic procedures,⁶⁹ then the mature minor doctrine will apply in even fewer cases. While this may be a satisfactory resolution of the problem for a few older minors, it will not have any applicability to the majority of minor donors who are children and young adolescents.

B. Substituted Judgment Standard

The substituted judgment standard is also not entirely satisfactory. In cases involving minors, the potential donors have never been legally competent and have, thus, never been able to provide the kind of legal evidence, such as prior gifts and expressions of intent, that courts eventually look to in determining what the wishes of the incompetent would be if he or she were competent. Consequently, it is argued that the court can only speculate as to what this minor might do if and when he or she became an adult. For example, the court in *Curran v. Bosze* stated that "[i]t is not possible to discover the child's 'likely treatment/nontreatment preferences' by examining the child's 'philosophical, religious and moral views, life goals, values about the purpose of life and the way it should be lived, and attitudes toward sickness, medical procedures, suffering and death.'"⁷⁰

If parents are given the authority to substitute their judgment for the child, they will undoubtedly be strongly influenced by what they hope their child would do if he or she were competent. Thus, parental aspirations for their child, usually including generosity and love toward the ill sibling, seem likely to bias the substituted judgment that they or the court reach for their child. Most courts have, thus, rejected the substituted judgment standard in the context of donations by minors because of the low degree of confidence they have in the prediction of what the child would do if competent.

C. Best Interests of the Child Standard

Most courts have, instead, adopted the best interests of the child standard. These courts argue that substituted judgment is not the appropriate standard to be applied because there is no previous period of competency upon which to base the substituted judgment.⁷¹ However, the best interests standard is itself unsatisfactory in that it fails to capture the nature of the decision to donate bone

⁶⁹ See *supra* note 37 and accompanying text.

⁷⁰ *Curran*, 566 N.E.2d at 1326 (quoting *In re Estate of Longeway*, 549 N.E.2d 292 (Ill. 1989)). See also Murphy, *supra* note 17. Murphy argues that in the case of a child there is "no period of prior competency upon which to evaluate his values, desires, or preferences in terms of the 'judgment' to be substituted. Thus, any meaningful effort to ensure respect for dignity and integrity of the incompetent individual or minor is necessarily undertaken without satisfactory guidelines or safeguards" and the analysis therefore becomes one of what is in the best interest of the child. *Id.* at 156.

⁷¹ See, e.g., *Curran*, 566 N.E.2d at 1319; Murphy, *supra* note 17, at 156.

marrow and, accordingly, does not further a respect for the personhood of the children involved.

Even very young children facing bone marrow harvests are often able to understand what is happening and why, at least on an elementary level. One nine-year-old donor described the process as: "They had to kill all his [her brother's] cells so my bone marrow and the stuff he had left would not fight. Then he had to have chemo and radiation and then they took the bone marrow from me and put it into him."⁷²

It has been suggested that under the best interests standard, the fact that the donor is willing to undergo the harvest should be used as evidence that the harvest is, indeed, in that child's best interests.⁷³ However, there is considerable evidence that decisions whether or not to donate tissue or organs are not governed by the type of thinking reflected in the best interests standard. That is, people undertaking to decide whether to donate do not tend to weigh the costs and benefits and to choose the alternative with the highest net benefit.⁷⁴

Simmons and her colleagues studied the decisions of donors and non-donors in the context of kidney transplants. They found that most people engaged in moral decision-making rather than following a rational decision process involving "deliberation and rational weighing of alternatives followed by a clear decision."⁷⁵ The process of moral decision-making involves awareness on the part of the potential donor that his or her actions have consequences for the welfare of another person, ascription of some responsibility to him or herself, and acceptance of a relevant moral norm (e.g., donation as an act of virtue or obligation).⁷⁶ The researchers gave examples of the responses of their subjects: "I didn't sit and consider the pros and cons. It was just a matter of priority and this was top priority." and "Me? I never thought about it. When we were typed

⁷²Interview with nine year-old bone marrow donor in Minneapolis, MN (February, 1994).

⁷³Baron et al., *supra* note 8, at 179.

A reasonable implication of this is that the individual's wishes should be accepted as evidence of his best interest, even when society believes that the individual is too young to make the ultimate choice himself. In transplant cases, it is suggested that courts treat the willingness of the prospective donor to participate as positive evidence that the donation would be in his best interest.

Id.

⁷⁴*See, e.g.,* Bernstein & Simmons, *supra* note 57; Fellner & Marshall, *supra* note 56; Roberta G. Simmons et al., *The Family Member's Decision to be a Kidney Transplant Donor*, 4 J. COMP. FAM. STUD. 88 (1973).

⁷⁵Simmons et al., *supra* note 74, at 89, 111-12. Fellner and Marshall report similar findings: "Our findings were surprising. Not one of the donors weighed alternatives and rationally decided . . . none had consulted his or her spouse." Fellner & Marshall, *supra* note 56, at 1247.

⁷⁶Simmons et al., *supra* note 74, at 92-93 (discussing Shalom Schwartz, *Moral Decision Making and Behavior*, in ALTRUISM AND HELPING BEHAVIOR 127 (J. Macaulay & L. Berkowitz eds., 1970)).

I automatically thought I'd be the one. There was no decision to make or sides to weigh."⁷⁷ Even those donors that did appear to have engaged in some weighing of costs and benefits utilized normative criteria in "the very weighing of costs against gains."⁷⁸

Bernstein and Simmons studied adolescent kidney donors and found that 50% of the adolescent potential kidney donors in their sample "made a rapid, instantaneous decision."⁷⁹ Similarly, when asked how the decision to donate bone marrow was made, one adolescent donor replied that while the choice was hers and that she could back out at any time, "there wasn't even a choice in it" because she loved her brother.⁸⁰

Thus, the decision whether to donate tissue or organs does not typically incorporate a rational weighing of costs against benefits. Accordingly, it is inappropriate to impose a decision that is the result of such a rational weighing on a minor who is capable of expressing his or her wishes. Robertson commented that "the presence of benefit does not justify nonconsensual intrusions on competent persons. Rather, the determinative factor appears to be consent or choice - persons may choose or consent to actions which bring them little or negative benefit. Respect for persons requires that incompetents be similarly treated."⁸¹

The lack of respect for persons implicit in the best interests standard in this context emerges in the fact that it fails to allow children to act altruistically. Rather, the best interests standard only allows children to act when it is in their own best interest. One commentator noted:

Unfortunately, the best interests of the child standard, as it now exists, suffers from an additional flaw: it imposes self-seeking values upon children. It permits children to act only when it is in their best interest, thereby foreclosing the possibility of altruistic or humane behavior. Such an impoverished vision of children based on net benefits fails to recognize the human element of childhood. Perhaps, then, what is most objectionable about the standard as it now exists is not that it imposes values on children, but that the values it imposes are the 'wrong' ones, i.e. they are too narrow. A better judicial approach to the best interests test would be one that nurtures altruistic tenden-

⁷⁷*Id.* at 96.

⁷⁸16% of their sample did not volunteer immediately but sought to further inform their decision. *Id.* at 103-04.

⁷⁹Bernstein & Simmons, *supra* note 57, at 1339.

⁸⁰Interview with adolescent bone marrow donor in *Lincoln*, NE (Spring 1993).

⁸¹John A. Robertson, *Organ Donations by Incompetents and the Substituted Judgment Doctrine*, 76 COLUM. L. REV. 48, 56 (1976).

cies and recognizes that children, as well as adults, enjoy giving for the sake of giving, and not just for some tangible reward.⁸²

D. Fairness and Reasonableness of the Parental Decision

The review of the fairness and reasonableness of the parental decision approach has been criticized in that it could lead to a donation that is against the potential donor's best interests.⁸³ This could occur in situations in which the donor's interests are outweighed by the recipient's and/or the family's interest. In these cases, the parents are, "[i]n effect, . . . given the authority to sacrifice the interests of the prospective donor if they reasonably conclude that the costs to him are outweighed by the potential benefits to the recipient."⁸⁴ Accordingly, proof of benefit to the donor would not be required under this standard.

While competent adults are not required to donate tissue or organs unless they consent even if it is in their best interest, this standard could require children to donate in a situation that is not in their own best interest and to which the child objects. To the extent that this is a criticism of a standard utilizing a review of the fairness and reasonableness of the parental decision, it is a criticism of all the standards discussed here. Thus, this standard is not unique in potentially imposing an obligation on minors that is not imposed on adults. Implicit in asking the question of whether and under what circumstances a minor who is legally unable to consent should be allowed to donate is the notion that some standard other than consent will be applied. Because minors cannot legally consent to the procedure, any standard (other than the mature minor standard) applied to allow donation cannot be based directly on the minor's consent.

An approach in which a court reviews the parental decision for fairness also suffers from the same infirmities as does the best interest of the child standard. Because it focuses, in part, on the best interest of the child, this approach fails to fully capture the nature of the decision to donate bone marrow. A review of the fairness and reasonableness of the parental decision merely increases the number of interests that are added to the equation, resulting in an even more extensive weighing of costs and benefits that show little regard for the non-rational, moral nature of the decision. Because a standard that approaches the analysis of the decision from a perspective of balancing costs and benefits misapprehends the fundamental character of the decision, it fails to further a respect for persons and does not allow children to act altruistically in the interests of another person.

⁸²Rachel M. Dufault, *Bone Marrow Donations by Children: Rethinking the Legal Framework in Light of Curran v. Bosze*, 24 CONN. L. REV. 211, 237 (1991).

⁸³Baron et al., *supra* note 8, at 172.

⁸⁴*Id.*

IV. EMPIRICAL STUDY

One way to preserve respect for persons and to allow children to act altruistically would be to revise the best interest standard to include the child's wishes and the benefits of acting altruistically as important factors. A second way to preserve such interests might be to resurrect the substituted judgment standard if empirical data supports the notion that the court can determine what the minor would do if he or she were competent. The doctrine of substituted judgment was developed in part to protect individuals' ability to choose their actions even if they were not able to assert their choices.⁸⁵ Incompetence seemed to be no reason to deprive them of their right to be generous or to make sacrifices that they did not directly benefit from. While it is impossible to know for certain what a particular minor would choose if he or she were competent, it may be possible to obtain empirical evidence to aid in estimating what minors would choose if competent. It would be instructive to know what competent adults would do under the circumstances in which minors are asked to donate to their siblings. If a significant number of adults would donate bone marrow under the operative circumstances, it could be used as evidence of what a minor under those same circumstances would choose to do if competent.⁸⁶

A. Operative Factors Used by Courts

Anecdotal information presented to some courts indicates that, in general, people do choose to donate tissue or organs to their brothers or sisters in order to save their lives. For example, in *Curran v. Bosze*, the court heard testimony from two doctors who indicated that in their respective experiences "100% of matched siblings have agreed to donate bone marrow to their siblings"⁸⁷ and that "[m]ost people inherently want to do it (donate bone marrow)."⁸⁸

The court opinions reflect a view of human relationships that suggests that the closeness of the relationship between the potential donor and the recipient as well as the availability of alternatives to the donation should affect the decision whether to donate tissue.⁸⁹ Given this conception of human nature, one would expect people to be less likely to donate when the relationship is more attenuated⁹⁰ and when there is an alternative available⁹¹ and vice-versa.

⁸⁵Robertson, *supra* note 81, at 63.

⁸⁶See *infra* notes 124-53 for a discussion of how this evidence relates specifically to the substituted judgment standard.

⁸⁷*Curran*, 566 N.E.2d at 1333.

⁸⁸*Id.* at 1336.

⁸⁹See, e.g., *Curran*, 566 N.E.2d 1319; *Richardson*, 284 So.2d 185; *Little*, 576 S.W.2d 493; *Hart*, 289 A.2d 386; *Strunk*, 445 S.W.2d 145.

⁹⁰See *infra* notes 92-101 and accompanying text.

⁹¹See *infra* notes 102-108 and accompanying text.

Thus, it would be informative to investigate whether the courts' assessment is accurate, that is, whether people would, in fact, most often choose to donate bone marrow to others and whether that decision is affected by the degree of relationship and/or by the possibility of alternate donors.

1. Relationship

Many courts, regardless of the standard applied, have focused, in part, on the relationship between the prospective donor and the recipient.⁹² For example, one of the three critical factors identified by the court in *Curran v. Bosze* was that:

[T]here must be an, existing, close relationship between the donor and recipient. . . . [T]he psychological benefit is not simply one of personal, individual altruism in an abstract theoretical sense, although that may be a factor.

The psychological benefit is grounded firmly in the fact that the donor and recipient are known to each other as family. Only where there is an existing relationship between a healthy child and his or her ill sister or brother may a psychological benefit to the child from donating bone marrow to a sibling realistically be found to exist. The evidence establishes that it is the existing sibling relationship, as well as the potential for a continuing sibling relationship, which forms the context in which it may be determined that it will be in the best interests of the child to undergo a bone marrow harvesting procedure for a sibling.⁹³

In a number of other cases the courts relied on evidence of a close relationship,⁹⁴ evidence of strong identification between the prospective donor and his or her sibling,⁹⁵ and predictions regarding the impact on the prospective donor were his or her sibling to die.⁹⁶

⁹² While the study presented in this article examines the type of relationship between the prospective donor and the recipient (i.e., parent-child, siblings, friends, strangers, etc.), it appears that courts also consider the quality or closeness of the relationship. See *infra* this section. There is some research regarding the closeness of the donor-recipient relationship currently being conducted. For a description of this research see Eugene Borgida et al., *The Minnesota Living Donor Studies: Implications for Organ Procurement*, in *ORGAN DONATION AND TRANSPLANTATION: PSYCHOLOGICAL AND BEHAVIORAL FACTORS* 108 (James Shanteau & Richard Jackson Harris eds., 1990).

⁹³ See, e.g., *Curran*, 566 N.E.2d at 1343-44.

⁹⁴ See, e.g., *Little*, 576 S.W.2d at 498 ("existence of a close relationship between Anne and Stephen, a genuine concern by each for the welfare of the other").

⁹⁵ See, e.g., *Hart*, 289 A.2d at 389 ("strong identification with her twin sister"); *Strunk*, 445 S.W.2d at 147 ("he identifies with his brother").

⁹⁶ See, e.g., *Hart*, 289 A.2d at 389 ("it would be a very great loss to the donor if the donee were to die from her illness"); *Little*, 576 S.W.2d at 498 ("awareness by Anne of

In the context in which the substituted judgment doctrine originated, deciding whether to distribute the property of an incompetent person, the relationship between the prospective donor and the recipient has long been an important factor. In *Ex parte Whitbread*, the court considered the degree of relationship between the incompetent person and the potential recipient in attempting to determine what the incompetent person would have done.⁹⁷ Also in the context of property distribution, it has been commented that, "[i]f evidence of past gifts or intention to give is absent, the closeness of the applicant's relationship to the incompetent may provide sufficient assurance that the incompetent would have made the gift if competent."⁹⁸

The following research empirically examines whether the relationship factor operates as a decision factor for adults presented with a donation decision. Specifically, it investigates general attitudes about sibling donation; whether adults think that a decision to donate is more likely to occur for siblings than for other types of relationships or non-relationships. There is some existing empirical evidence to indicate the accuracy of the courts' belief that donor-recipient relationship is a significant factor. Research has shown that altruism within the family is common in the context of kidney donation, but that the rate of offers to donate varies depending on whether the prospective donor is a parent, child, or sibling.⁹⁹ A study similar to this one asked students to indicate their willingness to donate various organs and tissues in a number of situations. Although the relative values for willingness varied across organs and tissue, in each case the relationship to the recipient was an important factor. Greater willingness to donate was shown when the recipient was the prospective donor's child or sibling and less willingness to donate was shown when the recipient was the prospective donor's friend or a stranger.¹⁰⁰ In another context, it was found that children are more likely to donate candy to a sibling than to a child they do not know.¹⁰¹

the nature of Stephen's plight and an awareness of the fact that she is in a position to ameliorate Stephen's burden").

⁹⁷*Ex parte Whitbread*, 35 Eng. Rep. 878 (1816).

⁹⁸Robertson, *supra* note 81, at 60. Even this inference may be more limited. Robertson continues: "This inference is usually confined to the immediate family—the spouse and minor children. It is sometimes extended to parents and adult children and occasionally to grandparents and siblings living with the incompetent. Beyond this immediate circle, courts have been reluctant to exercise their power of substituted judgement." *Id.*

⁹⁹Roberta C. Simmons et al., GIFT OF LIFE: THE EFFECT OF ORGAN TRANSPLANTATION ON INDIVIDUAL, FAMILY, AND SOCIETAL DYNAMICS 203-04 (1987).

¹⁰⁰James Shanteau & John J. Skowronski, *The Decision to Donate Organs: An Information-Integration Analysis*, in ORGAN DONATION AND TRANSPLANTATION: PSYCHOLOGICAL AND BEHAVIORAL FACTORS 59 (James Shanteau & Richard Jackson Harris eds., 1990).

¹⁰¹Hing Keung Ma & Man Chi Leung, *Effects of Age, Sex, and Social Relationships on the Altruistic Behavior of Chinese Children*, 153 J. GENETIC PSYCHOL. 293 (1992).

2. Uniqueness

Another factor emphasized by courts reviewing this issue is whether or not there are alternatives to the transplant (either other donors or other treatments). Courts approving transplants variously point out that the transplant is necessary to save the sick child's life,¹⁰² that there are no medically acceptable alternatives to a transplant,¹⁰³ and that all other living relatives have been tested and ruled out.¹⁰⁴ In contrast, the court in *In re Richardson*, in declining to authorize a kidney transplant from an incompetent to his sister, discussed the possibility of a transplant from another of her siblings.¹⁰⁵ The court stated that "neither a kidney transplant, nor particularly a transplanted kidney from Roy [incompetent prospective donor], is an absolute immediate necessity in order to preserve Beverly's life."¹⁰⁶

The following study also examines whether adults think that a decision to donate is more likely to occur when the actor is the only potential donor than when there is another equally appropriate donor. Previous research with kidney donors has found that willingness to donate varies with the number of other prospective donors available with people showing greater willingness to help if they are the only one available.¹⁰⁷ A similar phenomenon has also been demonstrated in the context of bystander research. Darley and Latané showed that people were less likely to offer aid in emergency situations when there were other people present.¹⁰⁸

B. Decisions Under the Operative Factors

This study was developed to assess the extent to which adults utilize information regarding the relationship between a prospective donor and recipient and whether there are other potential donors available in assessing an individual's likelihood of donating. Previous research has shown that many individuals, in responding to tests and inventories, tend to evaluate themselves in a socially desirable manner. Specifically, the more socially desirable an item or self-description is, the more likely it is to be marked as a description of the

¹⁰²See, e.g., *Hart*, 289 A.2d at 391 ("the operation on the donee is a necessity for her continued life"); *Strunk*, 445 S.W.2d at 145.

¹⁰³See, e.g., *Little*, 576 S.W.2d at 499 ("there were no medically preferable alternatives").

¹⁰⁴See, e.g., *Strunk*, 445 S.W.2d at 145; *Little*, 576 S.W.2d at 493.

¹⁰⁵284 So. 2d at 187. The siblings' tissue matches were not as close as was the incompetent's. There was a 4-5% risk of rejection of the incompetent persons tissue but a 20-30% risk of rejection of the siblings'. However, the court pointed out that successive transplants were not precluded. *Id.*

¹⁰⁶*Id.*

¹⁰⁷Simmons et al., *supra* note 99, at 219.

¹⁰⁸John M. Darley & Bibb Latané, *Bystander Intervention in Emergencies: Diffusion of Responsibility*, 8 J. PERSONALITY & SOC. PSYCHOL. 377 (1968).

test taker.¹⁰⁹ Further, it appears that there is extensive agreement on what behaviors are socially desirable.¹¹⁰ Because it is likely that donating bone marrow to save the life of another would be held by many to be socially desirable, subjects were asked to evaluate whether a third person would choose to donate in the situation described. It is hoped that the results are, therefore, more accurate estimates of the number of people who would actually donate in each situation.

1. Method

A group of 170 undergraduate students in introductory psychology classes at the University of Nebraska - Lincoln participated in the research in order to partially fulfill a course research requirement. The students had the option to do library research as an alternative to research participation.

The study utilized a hypothetical vignette about a decision whether to donate bone marrow. The vignette detailed a situation in which the actor was confronted with another person's need for a life saving bone marrow transplant and with the fact that his tissue matches that of the ill person's. The prospective donor was described as very fearful of medical procedures including needles. The ten versions of the vignette were identical except for the key phrases that described the relationship between the actor and the recipient and those that described the uniqueness of the actor's ability to donate. The relationship was varied such that the actor was either the recipient's father, brother, brother who was raised separately,¹¹¹ friend, or fellow community member. The uniqueness of the actor's ability to donate was varied in that either he was the only potential donor or there was an additional potential donor. In the cases where there was a second potential donor, both held the same relationship to the recipient (i.e., where the actor was the recipient's brother, the second potential donor was a brother as well). All the actors and recipients in the vignettes were held constant as males except where the second potential donor was the other parent - the mother.

The subjects were asked to indicate whether the actor would donate bone marrow on a scale of 1 to 5 with 1 indicating that the actor would definitely

¹⁰⁹Allen L. Edwards, *Relationship Between Probability of Endorsement and Social Desirability Scale Value for a Set of 2,824 Personality Statements*, 50 J. APPLIED PSYCHOL. 238 (1966); DOUGLAS P. CROWNE & DAVID MARLOWE *THE APPROVAL MOTIVE: STUDIES IN EVALUATIVE DEPENDENCE* (1964); Douglas P. Crowne & David Marlowe, *A New Scale of Social Desirability Independent of Psychopathology*, 24 J. CONSULTING PSYCHOL. 349 (1960); Allen L. Edwards, *The Relationship Between the Judged Desirability of a Trait and the Probability that the Trait will be Endorsed*, 37 J. APPLIED PSYCHOL. 90 (1953).

¹¹⁰Crowne & Marlowe, *supra* note 109, at 13.

¹¹¹The relationship of siblings raised apart was included to approximate the facts of Curran, 566 N.E.2d at 1319, in which the court declined to authorize a bone marrow transplant between half siblings who did not know each other.

donate and 5 indicating that the actor would definitely not donate.¹¹² The subjects were then asked to specify the importance of several factors (relationship, uniqueness, desire to help, and fear of the procedure) to the decision on a scale of 1 (very important) to 5 (not at all important).

Subjects were assigned to conditions through a block randomization procedure. One set of ten vignettes (one of each version) was randomly ordered and distributed to subjects, followed by the next set of 10, and so on. Each subject responded to one version of the vignette; therefore, a total of 17 subjects responded to each version.

2. Results

Overall, the mean decision rating was 1.93. The mean ratings for each of the ten groups are given in Table 1 and range from 1.35 (for a parent as the sole prospective donor) to 2.65 (for a community member as one of two prospective donors). Overall, 134 of the 170 participants (78.8%) answered on the end of the scale indicating that the actor would definitely donate or was likely to donate (ratings of 1 and 2 respectively).¹¹³ For the specific group of interest, siblings where no other donor is available, 15 of the 17 subjects (88.2%) responded that the actor would definitely or was likely to donate.¹¹⁴

Table 1: Mean Ratings for Relationship by Uniqueness
Donor's Relationship to Recipient

Uniqueness	Parent	Sibling	Friend	Sibling Raised Apart	Community Member	X
Unique Potential Donor	1.35	1.88	1.71	1.65	2.18	1.754 ^a
Non-Unique Potential Donor	1.59	1.76	2.12	2.41	2.65	2.106 ^a
X	1.47 ^{bc}	1.82 ^d	1.915	2.03 ^b	2.415 ^{cd}	

1 = would definitely donate 3 = neutral 5 = would definitely *not* donate
Pairs of letters indicate statistically significant differences at $p < .05$.

¹¹²This study did not address the moral or social dimensions of decisions to donate or not to donate bone marrow. The subjects were asked whether or not the actor would donate but not whether the actor should donate. It is possible that if adults commonly endorse or approve of decisions to donate bone marrow to critically ill siblings, there may be psychological benefits to children to do the socially condoned behavior. This is an area which could be explored by future research.

¹¹³54 of the subjects responded that the actor would definitely donate; 84 subjects responded that the actor was likely to donate.

¹¹⁴5 of the subjects responded that the actor would definitely donate; 10 subjects responded that the actor was likely to donate.

The decision ratings were analyzed using a between groups ANOVA procedure in order to investigate whether there were differences in ratings among the ten groups. Statistical analysis revealed a significant overall main effect of donor-recipient relationship ($F(1,160) = 6.986$, $p = .001$, $Mse = .565$). Overall, different relationships between the prospective donor and the recipient resulted in different mean ratings of donation likelihood. To determine specifically which groups had significantly different mean ratings, follow-up analysis was done using Bonferroni's multiple comparison correction procedure as well as Fisher's protected follow-up procedure. Both of these procedures revealed that subjects rated both parents and siblings as significantly more likely to decide to donate than community members ($F(1,160) = 26.8698$, $p < .005$, $Mse = .565$ and $F(1,160) = 10.6521$, $p < .005$, $Mse = .565$, respectively) and rated parents as more likely to donate than siblings raised separately ($F(1,160) = 9.4358$, $p < .005$, $Mse = .565$).¹¹⁵

Analysis also revealed a significant main effect of the uniqueness of the donor's ability to donate ($F(1,160) = 9.363$, $p = .003$, $Mse = .565$), with subjects assessing the actor's likeliness to donate as being higher when he is the only possible donor than when there is another potential donor. This effect was driven by the relatively larger simple effects of uniqueness that occurred when the recipient was a brother raised separately,¹¹⁶ a friend,¹¹⁷ or a community member.¹¹⁸

No significant interaction was shown between the donor-recipient relationship and the uniqueness of the donor's ability to donate as they influence the decision rating ($F(1,160) = 1.568$, $p = .180$, $Mse = .565$).¹¹⁹

¹¹⁵The reported values are statistically significant using Bonferroni's multiple comparison procedure. No significant differences in rating were found by either procedure between parent and sibling ($F(1,160) = 3.6858$, $p > .05$, $Mse = .565$), sibling and friend ($F(1,160) = .2715$, $p > .05$, $Mse = .565$), sibling and a sibling raised separately ($F(1,160) = 1.3269$, $p > .05$, $Mse = .565$), and friend and a sibling raised separately ($F(1,160) = .3979$, $p > .05$, $Mse = .565$). Using the Fisher's protected multiple comparison correction procedure, additional significant differences were found between the ratings of a sibling raised separately and a community member ($F(1,160) = 4.4599$, $p < .05$, $Mse = .565$), a friend and a community member ($F(1,160) = 7.5221$, $p < .05$, $Mse = .565$) and a parent and a friend ($F(1,160) = 5.9583$, $p < .05$, $Mse = .565$). Future research should attempt to more closely assess the differences, or lack thereof, between these types of relationships.

¹¹⁶This was the only simple effect that was statistically significant ($F(1,33) = 11.3613$, $p = .0020$, $Mse = .4375$).

¹¹⁷ $F(1,33) = 2.6667$, $p = .1123$, $Mse = .5404$.

¹¹⁸ $F(1,33) = 2.6945$, $p = .1105$, $Mse = .6985$.

¹¹⁹Some question is left regarding the interaction between relationship and donor uniqueness. While no significant interaction was found ($F(1,160) = 1.568$, $p = .180$, $Mse = .565$), the p -value for this interaction ($p = .180$) is relatively small. This could mean that there is, in fact, no interaction between donor-recipient relationship and donor uniqueness or this result could be due to sampling or to low statistical power. The main effect for uniqueness is driven by the statistically significant simple effect of uniqueness for a brother raised separately ($F(1,33) = 11.3613$, $p = .0020$, $Mse = .4375$) and the relatively large (but not statistically significant) differences for a community member

V. DISCUSSION

As discussed above, courts operate from a view of human behavior that suggests to them that they typically ought to allow minors to donate bone marrow to their ill siblings when there is a close sibling relationship and when there is no alternative course of treatment for the sick child.¹²⁰ Regardless of the standard applied by the courts, the result is that these harvests are generally authorized by the courts unless the relationship is attenuated or there are alternatives to the harvest.¹²¹ The results of this study shed some light on these assumptions made by courts by indicating how competent adults would choose to behave.

The data reported above indicate that as measured on a scale of 1 to 5 (definitely donate (1) to definitely not donate (5)), people are, in general, likely to donate bone marrow (average rating = 1.93). More specifically, the mean rating for the group rated as the least likely to donate, community members with a non-unique ability to donate (2.65), is still less than the scale mid-point of 3.00 (neutral). This suggests that regardless of relationship or uniqueness, subjects indicated that actors would be at least somewhat likely to donate bone marrow. Thus, given the opportunity, even donating bone marrow to a stranger was thought to be a socially likely behavior. In addition, however, the mean rating for the group most likely to donate, parents with a unique ability to donate (1.35), is greater than 1.00, indicating that not all subjects rated the decision as absolutely clear.

With respect to the specific group of interest, prospective donors who are siblings of the recipient where there is no other available donor, the data suggests that the factors considered by courts may affect decisions. The data demonstrated that siblings were rated as significantly more likely to donate bone marrow than were people who only had a community tie to the recipient.¹²² Further, the data revealed that for all prospective donors, whether there was another available donor had a significant effect on the decision. However, although the results indicate that siblings with a unique ability to donate were rated slightly more likely to donate than were those siblings for

and a friend ($F(1,33) = 2.6667$, $p = .1123$, $Mse = .5404$ and $F(1,33) = 2.6945$, $p = .1105$, $Mse = .6985$, respectively). This is consistent with the expected interaction pattern that the number of donors is less likely to matter when recipient is a family member because the actor would be willing to donate regardless of whether there are other potential donors (uniqueness is more likely to weigh in when the recipient is less close/unknown). Future research should continue to attempt to examine the precise nature of the interaction relationship.

¹²⁰See *supra* notes 87-108 and accompanying text.

¹²¹See *supra* note 60 for a discussion of those cases in which a harvest was not authorized.

¹²²See *supra* note 115 and accompanying text.

whom an alternative was available,¹²³ this factor was not statistically significant, possibly because siblings would be willing to donate to their brother or sister regardless of the other options.

A. A Revised Substituted Judgment Standard

The decision that a majority of people would make in similar circumstances may be a helpful piece of information that courts may use in substituting judgment for individuals who are incompetent to give legal consent. Courts have made clear that majority public opinion is not dispositive in the context of a substituted judgment. For example the court in *Superintendent of Belchertown State School v. Saikewicz* warned that:

[S]tatistical factors indicating that a majority of competent persons similarly situated choose treatment [do not] resolve the issue. The significant decisions of life are more complex than statistical determinations. Individual choice is determined not by the vote of the majority but by the complexities of the singular situation viewed from the perspective of the person called on to make the decision.¹²⁴

Adults do not always make the statistically likely choice. This was made clear by one commentator who pointed out that competent adults have refused to participate in bone marrow transplants even when there was little risk to them,¹²⁵ while other competent adults have participated in riskier activities to help another even though failure was likely.¹²⁶ Respect for persons demands that the individual be allowed to choose an unpopular or even irrational option.

However, in the case of an individual who has never been legally competent, such as a minor, there is little evidence of the person's needs, values, and desires. Substituted judgment is always a prediction, but when the child is able to give some assent to the harvest there is evidence of the child's current preferences. Although there is no prior period of legal competency, the substituted judgment standard can take into account present and future preferences in a "previewed judgment." Robertson identified the interests to be considered in the situation of a minor who "will attain competency in the future. . . . The interests to be maximized include the incompetent's existing tastes and preferences and the tastes and preferences the person is likely to have in the future when competent. Since the latter are unknowable, it would be in his interest to preserve maximum flexibility."¹²⁷ In this situation, evidence of

¹²³This difference was very small with only 0.12 points separating the groups. See table 1.

¹²⁴Saikewicz, 370 N.E.2d at 428.

¹²⁵See, e.g., McFall, 10 Pa. D.&C.3d at 90.

¹²⁶Adams, *supra* note 22, at 580.

¹²⁷Robertson, *supra* note 81, at 66.

majority sentiment, of what a reasonable person would decide, would be helpful as a statistical indication of what this particular person would decide. For example, if 90% of people in the same or similar circumstances as the individual would make a given decision, then, although it cannot be known with certainty how the individual would have decided were he or she legally capable, absent any other evidence, there is a 90% likelihood that the individual would make that same decision.

Courts have recognized the usefulness of this "indirect evidence."¹²⁸ In *Saikewicz*, the court considered evidence that most people in the incompetent's situation in that case would elect chemotherapy as an appropriate indicator of what he would have wanted. The court stated:

Evidence that most people would or would not act in a certain way is certainly an important consideration in attempting to ascertain the predilections of any individual, but care must be taken, as in any analogy, to ensure that operative factors are similar or at least to take notice of the dissimilarities.¹²⁹

In the bone marrow context, courts have identified the "operative factors" as including a close sibling relationship and the unavailability of alternative treatments.¹³⁰

The study presented above shows that, under the circumstances identified by the courts as operative, siblings where no alternative is available, 88.2% responded with a 1 or a 2 rating indicating that they would definitely or probably donate bone marrow. Thus, it could be argued that, all else being equal, there is an 88.2% chance that the minor would, if competent, be most likely to choose to donate bone marrow to his or her sibling. Although, as discussed below,¹³¹ the courts are unclear as to what degree of certainty is required, if even more certainty were required, the number of people who would definitely donate would be useful instead. Five of 17, or 29.4% of the subjects, responded that the actor would definitely donate. Thus, all else being equal, there is a 29.4% likelihood that a minor would, if competent, definitely choose to donate.

The size of the majority in agreement with a given decision that is sufficient depends, in part, upon the standard of proof to be applied. Courts have identified three standards of proof: proof by a preponderance of the evidence, which requires that the object of proof be more likely than not (this is used in most civil cases); the intermediate clear and convincing standard, used in "ex-

¹²⁸*Saikewicz*, 370 N.E.2d at 430.

¹²⁹*Id.* at 429. The court took such notice of the dissimilarities between the individual and the majority on the operative factors in deciding that treatment should not be given. *Id.* at 430.

¹³⁰See *supra* notes 87-108 and accompanying text.

¹³¹See *infra* notes 132-147 and accompanying text.

ceptional civil matters;¹³² and the strict proof beyond a reasonable doubt standard which is used in criminal cases. If the standard of proof is by a preponderance of the evidence, a smaller majority would be acceptable than if the standard of proof is beyond a reasonable doubt. For example, if 60% of people would make a given decision, this would be an indication, without any more evidence, that the individual in question would be more likely than not to make that same decision (proof by a preponderance of the evidence). However, this same 60% majority alone would not be an indication that the individual would, beyond a reasonable doubt, choose that same course of action.

In the "right to die" area, the area in which substituted judgment is predominantly used, the U.S. Supreme Court has ruled that it is permissible for a state to require proof of the individual's wishes by clear and convincing evidence.¹³³ However, the Court did not require the use of this standard. In the bone marrow context, most courts are not explicit about which standard of proof they are applying, using language such as "strong evidence,"¹³⁴ "substantial evidence,"¹³⁵ or "clearly."¹³⁶ The court in *Curran v. Bosze* discussed the substituted judgment standard extensively, and stated that such a standard requires proof by clear and convincing evidence, but then rejected the substituted judgment standard for making bone marrow donation decisions in favor of the best interest standard.¹³⁷ The court then found that the evidence "supported" the conclusion that the donation was not in the children's best interest.¹³⁸ In *In re Matter of Doe*, another best interests case, the court held that, "[r]egardless of the standard of proof that should be required in cases of this type, the record before us demonstrates by clear and convincing evidence that the procedure [bone marrow transplant] is in the incompetent donor's best interests."¹³⁹ Thus, it is not clear from the cases what standard of proof the courts use in this context (the substituted judgment standard or the best interest standard).

Even if it were clear what standard of proof was used, it would still not be clear how substantial a majority would be required to meet that standard. There

¹³²*In re Doe*, 481 N.Y.S.2d at 933.

¹³³*Cruzan v. Director, Missouri Dept. of Health*, 497 U.S. 261 (1990). Noting that the interests at stake in a right-to-die case are "more substantial . . . [than] a run-of-the-mine civil dispute," the Court allowed the state to "place an increased risk of an erroneous decision on those seeking to terminate an incompetent individual's life-sustaining treatment." *Id.* at 283.

¹³⁴*Little*, 576 S.W.2d at 500.

¹³⁵*Strunk*, 445 S.W.2d at 149.

¹³⁶*In re Richardson*, 284 So. 2d at 186.

¹³⁷566 N.E.2d at 1322-31.

¹³⁸*Id.* at 1345.

¹³⁹481 N.Y.S.2d at 933.

has been empirical research that has attempted to quantify standards of proof.¹⁴⁰ Simon and Mahan found that judges and students assigned an average probability of 89% to the beyond a reasonable doubt standard, while jurors assigned an average probability of 79% to this standard.¹⁴¹ The court in *United States v. Fatico* reported a study of federal judges in the Eastern District of New York whose responses in quantifying the beyond a reasonable doubt standard ranged from 76% to 95%.¹⁴² Regarding the preponderance of the evidence standard, Simon and Mahan found that this standard was assigned average probabilities of 61% by judges, 76% by students, and 77% by jurors.¹⁴³ The court in *Fatico*, however, reported that the judges variously quantified the preponderance of the evidence standard as more than 50%, 50.1%, and 51%.¹⁴⁴ The clear and convincing standard falls in between these. While Simon and Mahan did not include the clear and convincing standard in their study, the court in *Fatico* reported estimates ranging from 60% to 75%.¹⁴⁵ In addition, another survey of federal judges found a mean rating for the clear and convincing standard of 74.9%.¹⁴⁶ These wide ranges and overlapping values indicate that it is unclear what level of probability is indicated by any given standard of proof.¹⁴⁷ Even if it is not possible or desirable to articulate a

¹⁴⁰See Rita James Simon, *Judges' Translations of Burdens of Proof into Statements of Probability*, 13 TRIAL LAW. GUIDE 103 (1969); Rita James Simon, "Beyond a Reasonable Doubt" - An Experimental Attempt at Quantification, 6 J. APPLIED BEHAV. SCI. 203 (1970); Rita James Simon & Linda Mahan, *Quantifying Burdens of Proof: A View from the Bench, the Jury, and the Classroom*, 5 LAW & SOC'Y REV. 319 (1971). See also Francis C. Dane, *In Search of Reasonable Doubt: A Systematic Examination of Selected Quantification Approaches*, 9 LAW & HUM. BEHAV. 141 (1985) (comparing various methods of quantifying standards of proof) and Dorothy K. Kagehiro & W. Clark Stanton, *Legal vs. Quantified Definitions of Standards of Proof*, 9 LAW & HUM. BEHAV. 159 (1985) (comparing jury instructions in legal form, in quantified form, and in both for their effects of verdicts).

¹⁴¹Simon & Mahan, *supra* note 140, at 324.

¹⁴²458 F. Supp. at 410.

¹⁴³Simon & Mahan, *supra* note 140, at 327.

¹⁴⁴458 F. Supp. at 410.

¹⁴⁵*Id.*

¹⁴⁶C.M.A. McCauliff, *Burdens of Proof: Degrees of Belief, Quanta of Evidence, or Constitutional Guarantees?* 35 VAND. L. REV. 1293, 1328 (1982) (active, senior, and retired federal judges).

¹⁴⁷Indeed, many commentators and jurists have argued not only that quantification is difficult, but that it is inappropriate. Tribe exemplifies this view:

Of course the law could determine a numerical quantification on the level of doubt which is permissible. But the point is that the law does not do this. It leaves the standard of satisfaction vague. It requires a credibility statement that the facts in issue occurred beyond reasonable doubt and not a statistical statement that the probability of the facts in issue is 0.99 or 0.999 and so on.

Laurence Tribe, *Trial by Mathematics: Precision and Ritual in the Legal Process*, 84 HARV. L. REV. 1329, 1375 (1971). The Supreme Court has stated that "even if the particular

probability for the standard of proof to be applied, the same general principle operates in that the stricter the standard of proof to be applied, the more evidence (the more substantial majority) will be required.

In sum, in applying empirical evidence about how a substantial number of competent adults would behave under the circumstances, courts must compare the minority with the majority on the operative factors (here these are the sibling relationship and the lack of acceptable alternatives), articulate the appropriate standard of proof, and then apply the standard of proof to the evidence. When these or other operative factors indicate that the incompetent individual would not have decided as would most people, he or she must not be forced to conform to the majority.¹⁴⁸ By the same token, one who would, indeed, act in accordance with the majority must not be forced to act against the grain. Given no other information about the individual,¹⁴⁹ and given a match with the majority on the operative factors, the chances that the substitute decision will conform to the incompetent individual's actual choice is greater if the decision is made as the majority of people would have made it.

However, there is often more information on which to rely. When the minor is at least able to voice his or her assent to the harvest, the statistical results are only needed to bolster that assent. This would be a subjective form of substituted judgment that, instead of speculating about what the person would do if competent, would rely on what the minor would do if he or she had the legal capacity to decide. In other words, courts can expand the legal weight given to the minor's subjective choices even though he or she does not meet the standard for legal competence. Robertson noted:

If the incompetent lacks the capacity to communicate his preferences in the ways that people ordinarily do, it may be more difficult or perhaps impossible to know them. If he somehow communicates preferences, his very incompetency means that his preferences are not necessarily to be honored. But it would be erroneous to conclude that none of the expressed wants of incompetents should be satisfied. Incompetency encompasses several types of mental impairment, including the inability to have certain wants, the possession of bizarre wants, or the inability to choose among or satisfy conflicting preferences. Thus some expressed wants, if they appear irrational and indicative of his incompetency (such as a desire to fly) need not be

standard-of-proof catchwords do not always make a great difference in a particular case, adopting a 'standard of proof is more than an empty semantic exercise.' In cases involving individual rights, whether criminal or civil, '[t]he standard of proof [at a minimum] reflects the value society places on individual liberty.'" *Addington v. Texas*, 441 U.S. 418, 425 (1979) (quoting *Tippett v. Maryland*, 436 F.2d 1153, 1166 (CA4 1971) (concurring in part and dissenting in part), *cert. dismissed sub nom. Murel v. Baltimore City Criminal Court*, 407 U.S. 355 (1972)).

¹⁴⁸See, e.g., *McFall*, 10 Pa. D.&C.3d at 90; *Saikewicz*, 370 N.E.2d at 429.

¹⁴⁹Even *Strunk*, the only case to state that it was using the substituted judgement standard, used other information (i.e., the best interest of the child). 445 S.W.2d at 149.

honored. Expressed wants not in this category, however, should be satisfied. Clearly, they define, in part, his interests, of which respect for persons must take account.¹⁵⁰

Thus, the expressed assent of the minor combined with evidence indicating that most competent adults would choose to donate under similar circumstances provides the confidence required to substitute judgment for the minor while still respecting his or her personhood.

It is possible that the prospective minor donor may be so young that he or she is unable to communicate a preference regarding the potential bone marrow harvest. Under these circumstances, it may not be possible to have the requisite confidence to substitute judgment for the minor. Accordingly, it would then be appropriate to make a decision regarding the child or adolescent's participation under the best interest standard. "Where his wishes or intentions have not been articulated and cannot be known, the existence of net benefits serves as a convenient surrogate for determining what he would have chosen, because it is reasonable to assume that an incompetent would want that which benefits him."¹⁵¹ Use of this standard, however, must take into account the interest the minor has in behaving altruistically as well as the moral nature of the decision as described in the following section.¹⁵²

If the minor expresses the desire to not participate in the bone marrow harvest, such lack of assent by the minor should be taken seriously. However, in addition to protecting the minor's subjective choices, there is a need to protect children from the possibility of poor decisions that could have far-reaching effects. It is possible that the minor's refusal stems from irrational fears, such as fear of needles or hospitals, and as such are indicative of the minor's incompetence. Robertson would argue that these types of desires need not be honored.¹⁵³ However, while it should not be dispositive, the minor's refusal should be considered in the analysis of best interest as described in the following section. Such analysis may require stronger evidence of benefit than would be required to allow the harvest to proceed on a minor with no articulated preference.

B. A Revised Approach to Best Interests

An alternative or complimentary approach¹⁵⁴ to better ensure that minor bone marrow donors' interests in self-determination and in acting altruistically

¹⁵⁰Robertson, *supra* note 81, at 67.

¹⁵¹*Id.* at 57.

¹⁵²*See infra* notes 154-56 and accompanying text.

¹⁵³Robertson, *supra* note 81, at 67.

¹⁵⁴This revised best interest approach could operate as an independent standard for all minors. Alternately, it could be utilized as a compliment to the revised approach to substituted judgment, operating in those circumstances in which substituting judgment is not appropriate. *See supra* notes 151-53 and accompanying text.

are protected, is in a restructuring of the best interest of the child standard. Within the best interests standard itself, the law may give realistic protection of the self-determination and selflessness of potential minor donors. However, to do so requires an articulation of appropriate factors for courts to balance in reaching their determinations that includes the wishes of the minor. Such factors might include: the minor's capacity to appreciate the risks and benefits of a bone marrow harvest; the minor's capacity to appreciate the nature of the potential recipient's condition; the minor's relationship to the potential recipient; the minor's wishes regarding the harvest; the parent's wishes regarding the harvest; the availability of a primary caregiver to provide emotional support to the minor; and the risks and benefits of the procedure to the minor (including psychological risks and benefits if they can be reasonably estimated).

This best interests test includes the minor's wishes as an important factor to be considered in determining whether a harvest is appropriate. The minor's wishes are included in the test, not to assist the court in substituting judgment for the minor, but because protecting the minor's ability to decide is likely to advance the minor's best interests. The minor's preference will allow factors of altruism, compassion, and courage to be included in the decision, through the minor's own input, rather than through the decision-making of a substitute.¹⁵⁵

Such a restructured best interest of the child standard allows courts to evaluate the minor's wishes in light of the minor's understanding of the recipient's condition as well as of the bone marrow harvest itself. Considerable weight could be given to the wishes of children and adolescents who display a basic understanding of the situation. Alternately, minors who do not manifest such an understanding would not have their wishes considered as strongly. Thus, as under the substituted judgment standard as reevaluated above, the basis of the minor's desires ought to be considered and used to assign weight to those desires in the best interests balancing.

Accordingly, the assent of a minor who displays a basic understanding of the situation ought to be given substantial weight, while the assent of a minor who does not show this basic comprehension ought to be considered less

¹⁵⁵This respect for the child's wishes should not be taken to mean that all minors who are so capable must be forced to express a preference. Buchanan and Brock expressed this concern:

Nothing in our analysis above or the policy implications discussed below implies that children should be forced, pressured, or even encouraged to decide about health care for themselves when they do not wish to do so. If a child, for example, does not feel emotionally prepared to take responsibility for a difficult treatment decision, then even if his or her other decision-making capacities appear well-developed it could be harmful to the child to have to take responsibility for the decision. Waiver by competent adults of their right to give informed consent and their transfer of that right to others is well recognized in medical practice, medical ethics, and the law, and deserves to be equally honored for competent minors.

BUCHANAN & BROCK, *supra* note 14, at 240.

important in the balance. Similarly, the expressed desire of a minor not to participate in the harvest ought to be given more emphasis in the balance when that minor manifests a basic understanding. In the case of a minor's refusal to participate, however, the court ought to look, in addition, at the reasons for the refusal in order to determine whether they are, as Robertson put it, "indicative of his incompetency."¹⁵⁶ If the minor is unable or unwilling to express a preference, then the balancing analysis may continue without the child's wishes as a factor. In all cases, however, the value of acting for the benefit of another ought to be considered in the weighing process.

The best interest of the child standard, as described here, includes self-determination as an important factor to be considered in cases in which the prospective donor, even if not legally competent, can articulate his or her wishes regarding a bone marrow harvest within the context of his or her understanding of the existing situation. While the revised standard continues the use of weighing factors to determine best interests, it includes moral interests in self-determination and altruism as worthy of consideration.

VI. CONCLUSION

There are several approaches that courts take to the difficult question of whether a healthy minor ought to be allowed to donate bone marrow to a critically ill sibling and different legal underpinnings are utilized to analyze the problem of informed consent in this area. The mature minor doctrine, the substituted judgment standard, the best interest of the child standard, and court review of the fairness and reasonableness of a parental decision, have all been relied on by courts in addressing these issues. However, none of these standards has provided an entirely satisfactory framework in which to base these decisions: the mature minor doctrine does not apply to the majority of cases; the substituted judgment standard fails in the face of concerns about prediction; and the best interests and parental review standards fail to accurately reflect the moral nature of decisions whether to donate tissue.

The proposed modified standards attempt to remedy these deficiencies. The revised substituted judgment standard combines empirical data demonstrating decisions under the factors courts have defined as operative with the assent of the minor to enhance confidence in predicting what that minor would decide if competent to do so. In cases in which the assent of the child is unavailable or untrustworthy, reliance must instead be placed on a modified best interests of the child standard. This revised best interest approach (which may also operate as an independent standard for all minors) attempts to introduce the wishes of minors who comprehend the situation and the value of altruism into the best interest balancing equation. These revised standards provide a more solid legal grounding for decisions involving minors and bone marrow donations and incorporate a greater degree of respect for the choices of minors.

¹⁵⁶Robertson, *supra* note 81, at 67.

