

Using Children as a Means to a Sibling's Health

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Sibling Donation is Well Accepted in
Pediatric Transplant Community.

Widely Assumed Donors Benefit.

“I do not believe that a day of minor discomfort and an extremely small risk of anesthesia outweigh a lifetime without a healthy older brother or sister and the years of joy it potentially brings.”

Month. BMJ 1996; 312:240-243



Court Cases: Allow Donations Due to Benefit to Donor

Hart v. Brown 1972 Court approved kidney donation for twin due to

“immense benefit to family....would be a great loss to the donor if the donee were to die from her illness.”

Court Cases: Donations Allowed Based on Benefit to Donor

- **Masden v. Harrison (1957)** continued survival of brother essential to psychological health of donor.
- **Strunk v. Strunk (1969)** brother closest friend.
- **Little v. Little (1979)** donor emotionally close and might be harmed if not allowed to donate.

Court Cases: Not Allowed if No Benefit

Curran v. Bosze (1990): Three conditions necessary to show in minor's best interest:

1. Parent consents and is informed.
2. Emotional support available to minor.
3. "Existing, close relationship between donor and recipient."

Curran v. Bosze (1990)

- Father wanted half-sib living with mother tested for donation to child living with him.
- Half-sibs did not have a close relationship.
- No consent from mother.
- Donation not allowed.

Do Donors Benefit?

Adult unrelated solid tumor donors benefit:

- Increased self esteem
- Pride in donating
- Feel like better persons
- Increased meaning and worth of life

Switzer, GE et al, in *The Transplant Patient: Biological, Psychiatric, and Ethical Issues in Organ Transplantation*, Trzepacz and DiMartini, eds. 2000, Cambridge University Press: Cambridge. p. 42-66.



But What About Minor Related BMT Donors?

Only Four Small Retrospective Studies

Packman et al.

- 21 donor siblings; 23 non-donor siblings.
- 6 to 18 yo at time of data collection.
- 3 to 3.5 years post-transplant.

Packman et al. J Ped Onc Nur 2004;21:233-248

Packman et al. J Psy Onc 1997;15:81-105

Packman et al.

Sibling donors compared to non-donors

- Higher levels of anxiety
- Lower self-esteem
- Lack of choice
- Higher levels of depression *
- More posttraumatic stress *

* trend, not significant

Packman et al.

Parents report

- Donors more depressed and withdrawn.

Teachers report

- Donors showed more leadership and adaptive skills.

MacLeod et al. Donor Sibs

- Successful transplants (n=8)
- Unsuccessful transplants (n=7)
- Qualitative retrospective study
- 12 to 28 yo
- Transplants 2-15 years prior

MacLeod et al, J Ped Psy 2003;28:223-231



MacLeod et al. Successful Transplants

- Increased self-esteem
- Improved relationships within the family
- Increased knowledge of sibling's disease
- Decreased feelings of helplessness



MacLeod et al. Successful Transplants - Some Negative Sequelae

When sib developed severe or long-lasting complications, donors report

- » Guilt
- » Sadness
- » Worry



MacLeod et al. Unsuccessful Transplants

Positive overshadowed by

- Guilt
- Shame
- Anger

Snethen and Broome

Interviewed 19 siblings of children with chronic diseases.

Sibs report:

- Concern about sick sib.
- “Outside the circle” of decision making and discussion.
- Increased workload at home.
- Increased loneliness.

Snethen JA, Broome ME: Journal of Family Nursing 2001;7:92-110

Snethen and Broome

6 of 19 sibs were BM donors.

Donation allowed them to “join the circle.”

Reluctant to undergo second donation

- Pain
- Worry about efficacy

Wilkins and Woodgate

- 8 female sibs of 7 BMT patients, 11-24 yo at time of interview.
- 3 of 8 were donors.
- Mean 4 years post transplant.
- Main theme: Interruption in Normal Family Life.

Wilkins, Woodgate. *Onc Nurs For*. 2007;34:E28-35



Interruption in Family Life

“The extra responsibility—honestly, I was ticked off. I didn’t want it. I didn’t understand why it had to be all me.”

The BMT Experience was Similar for Donor and Nondonor Siblings

- Sibs good days and bad days mirrored ill child's trajectory.
- Feelings of isolation felt as significant loss.
- Great need to feel part of the family.
- Want to “be with” their parents and
- “be there” for their ill siblings.



More Data Necessary to Determine if Donors Benefit

The small, retrospective studies hint at some negative sequelae.

Sibling and Donor: Adored and Ignored



Video file...
Ridgeway.wmv



Proposed Ethical Justifications for Sibling Donation

1. Best Interest – data scanty.
2. Intrafamilial
3. Intimacy
4. Duty



Intrafamilial Justification for Minor Donation

The needs of the entire family must be weighed, allowing one family member's benefit to be traded off for another's benefit.

Nathan v. Farinelli (1974)

Intimate Attachment Principle

One's life is diminished when anyone, family member or not, dies and so a minor's interests are served by being allowed to donate bone marrow to an intimate friend as well as a family member.

Jansen. Cambridge Quarterly 2004;13:133-142

Intimate Attachment Principle

Ross believes that intimacy is the basis of familial obligations.

Caveats:

1. Cannot sacrifice basic needs of child. Can minimally compromise one child's health for the good of the family, since well being of family impacts well being of child.
2. If the intimate other is not a family member, Ross requires outside review.

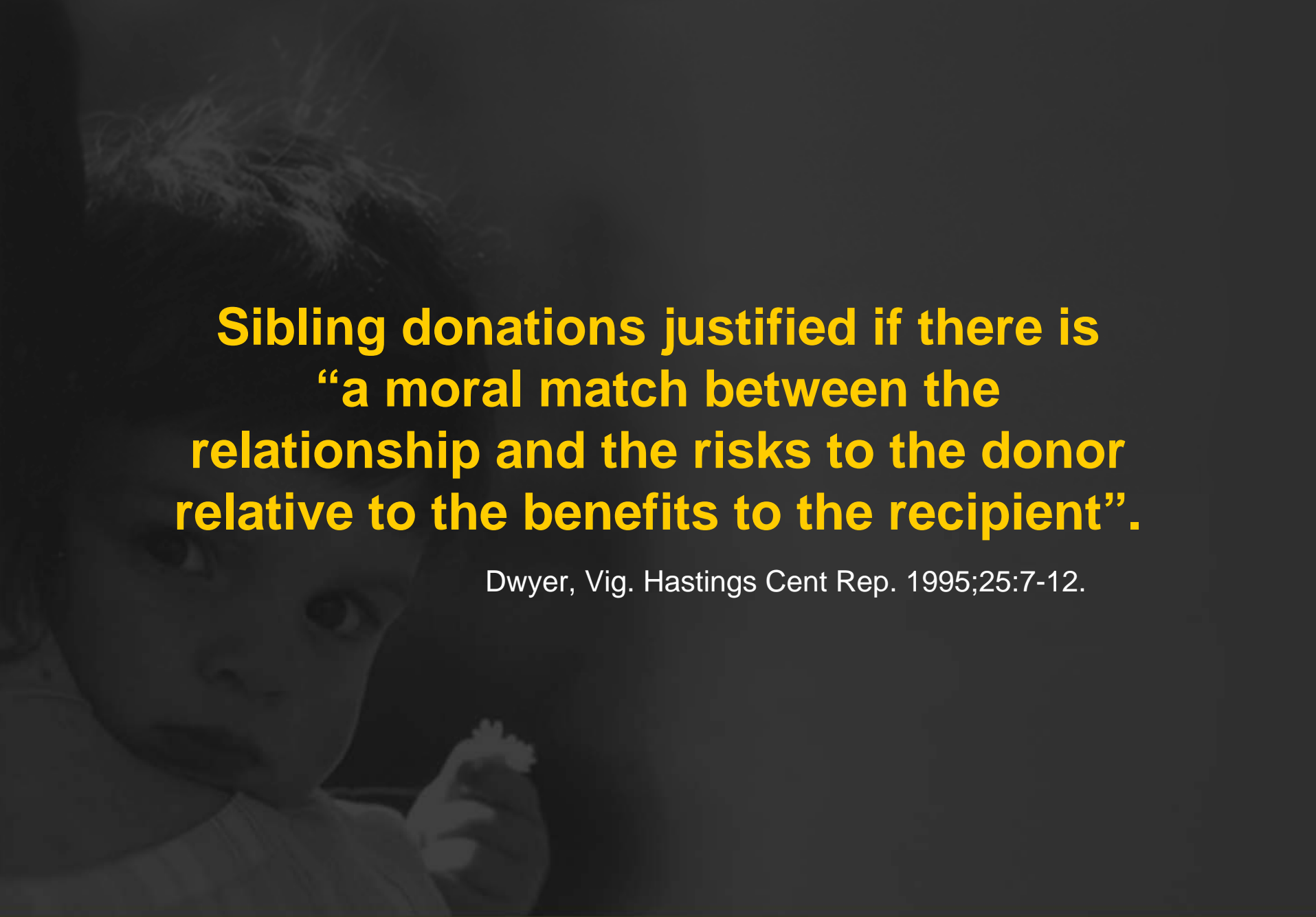


Duty Justification

Family members have obligations to one another that require sacrifice of one family member's benefit, in certain circumstances, for the benefit of another family member.

Duty Justification

- Familial obligations not based entirely on intimacy – we require child support from non-intimate fathers.
- Only a prima facie duty to donate to a family member. Can be overridden if risk too high. Cannot donate a heart.



**Sibling donations justified if there is
“a moral match between the
relationship and the risks to the donor
relative to the benefits to the recipient”.**

Dwyer, Vig. Hastings Cent Rep. 1995;25:7-12.

Altruism

- Motivated primarily by respect and concern for the interests and needs of others
- No special relationship to recipient
- Freely chosen
- Not done out of duty or obligation
- Involves some cost or risk

Glannon and Ross Cambridge Quarterly 2002;11:153-159



Can Family Members Act Altruistically?

Yes, if the prima facie duty is overridden and the family member still decides to proceed.

Pentz. J Clinical Ethics. 2006;17: 227-230.

Problematic Differences in Treatment of Adults and Children

- McFall's adult cousin did not have to donate BM.
“One human being is under no legal compulsion to give aid or to take action to save [another] human being....[yet] in the view of the courts, the refusal of the defendant is morally indefensible” McFall v. Shimp
- Adults can create mock reasons not to donate.

Discussion Case #1

- Vietnamese woman “adopted” by couple in North Carolina.
- She lives with them for 2 years. Has a daughter. Moves alone to Texas. Couple adopts the daughter.
- Mother has no contact with daughter for 4 years.
- Mother needs BMT.

Discussion Case #1

- Couple agrees to testing. Child is histocompatible.
- Couple told would have BM donation.
- When arrive in Houston, find out it will be stem cell donation.
- Child refuses.
- Couple torn. Request ethics consult.



Discussion Case #1

What do you recommend?

What is the ethical justification for this recommendation?



My Sister's Keeper Jodi Picoult

- Anna conceived to be match for sister, Kate, who has APL.
- Has donated cord blood, lymphocytes 3X at 5yo, BM for transplant, granulocytes, stem cells.
- Now parents expect her to donate a kidney at 13.

Anna Sues for Medical Emancipation

Lawyer: “Obviously you agreed to be a donor for your sister before.”

Anna: “Nobody ever asked.”

Lawyer: “Did you tell your parents you don’t want to donate a kidney?”

Anna: “They don’t listen to me.”

Anna and Jesse

- Anna's reason for refusing: "Because it never stops"
- At 11, Anna starts playing hockey. Parents have no clue until she asks for money for equipment.
- Anna feels invisible except when medically needed.
- Brother becomes a pyromaniac because he feels like he is only smoke.



Mother before BM donation

“You don’t have to do this if you don’t want to, but I know that Kate is counting on you. And Daddy and me.”

After BM Donation

“Mommy” she sobs. “It hurts.” I sit down on the side of the bed and fold her into my arms. “I know, sweetie.”

“Can you stay here?”

I shake my head. “Kate’s sick. I’m going to have to go back.”

“But / am in the hospital!”



Discussion Case #2

Should Anna donate the kidney?

Should Anna be medically emancipated?

What are the ethical justifications for each position?

Discussion Case #3

- David, 17 yo, wants to donate kidney for brother.
- “I want to donate my kidney because then I will be a hero to my family.”
- Understands risks and that he will have to give up football.
- David’s very close family supports him.

Rhodes, Mt Sinai J Med 1993;60:45-50

Discussion Case #3

Rhodes' questions:

1. Does David realize this limits his career choices – military service, law enforcement?
2. Is his “close” family coercive?
3. Is his motivation akin to that of a family “black sheep” who wants to regain status? Simmons, Gift of Life 1987: black sheep may not do as well.

Discussion Case #4

- 8 yo with thrombocytopenia develops aplastic anemia at 15 mo post diagnosis.
- Now refractory to random donor platelets.
- 9 yo brother is histocompatible. Under a psychiatrist's care but donation not deemed potentially damaging psychologically.

Levine, J of Ped. 1975;86:145-150.

Discussion Case #4

- Parents accuse physician of delaying diagnosis of anemia in order to study son.
- Father alcoholic.
- Parents refuse transplantation.
- 3 months later child dies.

Should the hospital/physicians have acted differently?

Discussion Case #5

- Father has leukemia, needs BMT
- 3 months old child, 1/10 the weight of her father, good match
- Father consents for donation
- Risk: Marrow must be harvested from both hips, requiring a turn under anesthesia, increasing risk.
- The anesthesiologist requests an ethics consultation.

Discussion Case #5

- Risk of anesthesia – not known in pediatrics. Risk of adult mortality is 1 in 339,450. Brown. Risk and Outcome in Anesthesia 1992.
- Other risks – may be over 100 sticks into bones. Small risk of permanent nerve damage. Increased risk for infection while bone marrow replenishes.



Discussion Case #5

What should the Ethics Consult Recommend?

Pentz et al. Cambridge 2004;13:149-155

Discussion Case #6

- 7 week old premature baby is match for urgent BMT
- Took two-thirds of the babies blood volume – recipient couldn't wait.
- Donor transfused and volume resuscitated.
- Donor subjected to invasive monitoring of intravascular pressures.

Urban et al. Bone Marrow Transplantation. 1990;6:443-4