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THE CHILD AS TISSUE AND ORGAN DONOR

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March 1996

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfilment of the requirements of the degree of Master's of Arts in Philosophy, Specialization in Bioethics.

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Abstract

This thesis attempts to answer the following question: Is it ever morally permissible to use a minor child as a tissue or organ donor for the benefit of a family member? Those sceptical of using minors as tissue or organ donors for the benefit of a sick family member will highlight two points: the donor will be subject to risks that are not counterbalanced by possible medical benefits, and the minor cannot consent to the procedure herself.

This thesis will present a review of the medical risks associated with bone marrow and kidney donations, as well as a review of the common law dealing with donations by minors and incompetent persons. The final chapter then makes a case for the permissibility of minor donation based on the interests of the family.

Résumé

Cette thèse cherche à répondre à la question suivante: est-il moralement acceptable qu'un enfant mineur fasse don de tissus ou d'organes à un membre de sa famille? Ceux qui ont des réticences à accepter que des mineurs puissent faire don de tissus ou d'organes à un membre malade de leur famille font valoir deux arguments: le donneur s'expose à des risques qui ne sont nullement contrebalancés par des bienfaits médicaux et le mineur ne peut consentir à la procédure.

Cette thèse passe en revue les risque médicaux liés aux dons de moelle osseuse et de rein ainsi que les aspects de la *common law* portant sur les dons d'organes ou de tissus faits par des mineurs et des personnes incompétentes. Le dernier chapitre présente des arguments en faveur de ce type de don, leur caractère acceptable étant fonction des intérêts de la famille.

Preface

I have benefited from the assistance of many people during the course of writing this thesis and I would like to give thanks here. First, for permission to read her unpublished Ph.D. Dissertation, I would like to thank Lainie Friedman Ross of the University of Chicago. For very helpful comments on chapter 2, I would like to thank the following two people: physician-philosopher Charles Weijer and David McKay, kidney transplant surgeon. For very helpful comments on chapter 3, I would like to thank the following two people: Shauna Van Praagh, professor of law and Kathleen Cranley Glass, lawyer-ethicist. I would like to thank Dr.Glass further for the loan of reference materials and for a brief but informative discussion of the ethics of kidney donation by children.

For many reasons, special thanks must go to my supervisor Carl Elliott. First, for his patience for the months that passed when I told him that I was writing, when really I was reading. I owe Carl a special debt of gratitude for investing so many hours into this project, for keeping me on track and for making the final product far better than it would otherwise have been. Thanks again to him for employing me as a research assistant which enabled me to remain in Montreal for the duration of the thesis writing. A final thanks to Carl for introducing me to three lifelong friends: Binx Bolling, Will Barrett, and Bourbon. All of them kept me company throughout the writing of the thesis, and all were essential to help bring to articulation what the reader now has before his or her eyes.

To many friends I owe thanks: for their kindness, their judgement and for their patience in listening to me (yet again) talk about children donating their kidneys. For being there, and for always helping me, I give thanks to Anna Zalewski. The family figures very prominently in these pages, and I will dedicate this thesis with love to my own extended family. In particular, I dedicate this work to my parents, Elizabeth Maria and Robert Edmund, they put me on this planet after all.

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Now, as I have already insisted, few of us are tender-foot Bostonians pure and simple, and few are typical Rocky Mountain toughs, in philosophy. Most of us have a hankering for the good things on both sides of the line. *Facts are good—give us plenty of facts. Principles are good—give us plenty of principles.*

William James
Pragmatism 1907

You see, I know that it's difficult to think *well* about 'certainty', 'probability', 'perception', etc. But it is, if possible, still more difficult to think, or *try* to think, really honestly about your life and other people's lives. And the trouble is that thinking about these things is *not thrilling*, but often downright nasty. *And when it's nasty then it's* ***most*** *important.*

Ludwig Wittgenstein
Letter to Norman Malcolm 1944

The problems are solved not by giving new information but by arranging what we have always known.

Ludwig Wittgenstein
Philosophical Investigations 1953

Chapter 1

Introductory Themes

§1.0 Introduction

Before proceeding to outline this work chapter by chapter, it will be useful to articulate the problem that will be the subject of this inquiry. Insofar as one can condense a complex problem into *one* question, in this case that one question would be the following: Is it ever morally permissible to use a minor child as a tissue or kidney donor for the benefit of another member of his or her family?

Why might such donations present a problem? It is a widely accepted proposition that the consent of a competent patient must be secured before any medical intervention is initiated. When the patient is incompetent, as is a child, consent must be sought from someone other than the patient himself or herself — usually the parents. Central to the conventional decisionmaking framework employed by parents for their children is the "best interests" standard. To use the best interests standard in one's deliberations is to say that the focus of the decisionmaking deliberations is whether or not the proposed course of action will be in the child's best interests, however those interests happen to be defined. This is not to say that decisions made for children should be done with the aim of *optimizing* their interests. Rather, it is to say that decisions should be made for children such that their interests, however defined, guide decisionmaking.

Traditionally, parents, as the primary child-rearers, have been allowed to exercise their discretion when acting as decisionmakers for their children: the school the child will attend, what church (if any) the child will be a member of, and which activities the child will engage in are, *inter alia*, issues which fall under the umbrella of parental authority. Parents, it is reasonable to assume, know better than anyone else what is and is not in the best interests of their child; presumably, as well, parents will naturally let the best interests of their child guide their decisionmaking. In situations where an intervention is for the direct benefit of the child — as, for example, in smallpox vaccination — most parents would agree to subject their child to the pain and risks of receiving a needle because the anticipated benefits would outweigh the risks to the child. However, we brush up against the limits of parental authority when parents make decisions which entail the infliction of a bodily and/or psychological harm on their child where the harm is not counterbalanced by sufficient benefit.

Baldly stated, the problem raised by child organ and tissue donation is the following: if children cannot themselves consent to donate, then it must be shown that the procedure carries an acceptable risk/benefit ratio; but tissue and organ donation, at least on the surface, does not appear to carry an acceptable risk/benefit ratio. Therefore, in consenting to such procedures, parents are allowing their child to be subjected to a procedure that carries potentially serious physical risks but which offers no hope of *physical* benefit to the child.

However, if "best interest" is interpreted broadly to include both physical *and* psychological components, as it has been by many courts, the determination of what course of action will or will not be in the child's best interests can become a matter of serious debate. For example, if the transplantation is a success, is there not a great psychological benefit to be gained for the donor from having donated her bone marrow or kidney to save the life of her sibling? Would such a child donor not benefit greatly, first, from being able to grow up with her now healthy sibling at her side, and second, from knowing that she had been instrumental in saving her sibling from death? If one views the avoidance of a harm as beneficial, then it is reasonable to suggest that the donor, by saving her sibling's life, is spared the trauma of having to deal with the death of a sibling.

Of course, the harms attending the transplantation procedures may not all be physical. There will always be a significant probability, higher for some patients and procedures than for others, that the transplantation will be a therapeutic failure. If, for example, the transplantation is performed but the recipient dies, or if the graft is rejected, the donor may consequently suffer a psychological harm by believing that *she* killed her sibling, or that *she* did not do enough to save her sibling. On the other hand, it is not implausible to suggest that the donor may, perhaps not initially but ultimately, be comforted by knowing that she was instrumental in her sibling's medical care even if her donation proved to be ineffective in the end.

An ethical analysis of the permissibility of using children as organ donors, then, becomes far more complex when the best interests standard is interpreted broadly; and this analysis can be made more complex yet. In particular, the parents who must deliberate about whether or not their healthy child will serve as a donor for the benefit of their sick child must consider both of their children when they weigh the risks and benefits of the proposed procedure, if not the interests of the family unit as a whole. Moreover, parents will themselves have interests that are affected by the outcome of the medical intervention; they too will suffer if their sick child dies. A recognition of this shift in deliberative focus might make one question whether or not parents in this situation are sufficiently impartial to make a choice for their healthy child guided by that child's best interests.

As we have seen, the problem surrounding the use of children as organ and tissue donors is thorny. Assuming that the bone marrow or kidney harvesting is successfully carried out and the donor recovers without complication, it seems that great good can come out of using the child as a donor: the donor recovers unproblematically, the recipient is given new hope in life, the family remains united and avoids the suffering and pain that would have come with the death of a child. But the issue is more involved; the donor *can* suffer great harm and die, the recipient can die *despite* the transplantation, and the family can compound its suffering and pain in the process. This essay is an attempt to determine how best to think about this issue.

The brief discussion above introduces some of the issues that surround the focus of this work, namely, an examination of the moral permissibility of using children as kidney donors or as bone marrow donors for the benefit of another family member. I would like to make four prefatory points, however. First, the use of the term "child" will be taken broadly to mean "legally incompetent by virtue of age." This means that highly intelligent twelve year-olds who understand the implications of donating bone marrow and wish voluntarily to do so will fall within the domain of our analysis.[1] Although certain issues surrounding the "use" of mentally incompetent adults as organ donors will inform the analysis presented herein, mentally incompetent adults as a class will fall outside the domain of inquiry.

Second, the analysis will focus solely on intrafamily donations where the child serves as the organ or tissue donor; in other words, we will be looking almost exclusively at donations between minor siblings, although the analysis presented may have implications for less frequent child-to-parent donations. An examination of the permissibility of using children as organ or tissue donors for unrelated recipients will not be undertaken for two main reasons. First, for reasons relating to a lack of histocompatibility, organ and tissue donations to non-family members will rarely be a biologically optimal option.[2] Second, there will emerge certain features of what can be termed the morality of intimate relationships which will raise a presumption against donations by minors to non-family members.

The third prefatory point is that it is reasonable to put forward some guidelines as to the conditions that should be satisfied before a child is considered to act as a tissue or organ donor. For example, the sick patient should be in urgent need of either a kidney transplantation or a bone marrow transplantation in order to maintain his or her health; if other therapeutic regimens offer equal chances of recovery or survival for the patient, then these therapeutic avenues should be explored before exposing a child unnecessarily to the risks of bone marrow or kidney harvesting. Thus, for example, if a non-ablative chemotherapy is therapeutically equivalent for the cluster of cancers for which bone marrow transplantation is indicated, then the bone marrow transplantation need not be considered first. In addition to this, it seems reasonable to establish that the competent adult members of the family are ineligible to donate before one approach the child. If an adult can bear the burden then it seems that he or she should bear the burden; after all, adults can engage in risky behaviour with more foreknowledge of the significance of the consequences and thus more responsibly than can children. The issue of establishing preconditions (guidelines) for the use of child donors is elaborated on below in chapter 4.

Finally, the issue of whether or not the improved therapeutic outcome for the recipient resulting from the use of live donors (as opposed to cadaver donors) can justifiably be purchased at the cost of imposing potentially serious risks on a child donor will not be addressed in a detailed manner. This is not an issue that can be determined *a priori*, but rather is one that will be a matter of clinical, parental and ethical judgement. It is worth noting that there is no uncertainty in the community of expert clinicians concerning the relative effectiveness of live versus cadaveric renal donation: renal donation from a living related donor offers better graft and patient survival rates than those observed with cadaver donors[3]; and the outcome is best when the donor and recipient are closely matched histocompatible siblings. The importance of this point is simply that as long as the use of a sibling donor is the intervention which guarantees the highest probability of therapeutic success for the recipient, parents will be faced with the decision of whether or not to allow their healthy child to serve as an organ donor for the benefit of their sick child.

§1.1 A look ahead

In an attempt to prepare the reader for what is in store, I now turn to a chapter by chapter synopsis of the essay, introducing the guiding concepts and the questions to be answered in each chapter.

The writings that deal with the issue of the child as donor are few but share the characteristic of being very brief in their discussions of the risks and benefits that can accrue to the child who serves as either a kidney or bone marrow donor. The aim of chapter 2 will be to get a clear sense of what burdens the kidney or bone marrow donor must bear, as well as what possible benefits might accrue to the donor. Therefore, I will address the following broad question: what are the medical risks, both short-term and long-term, involved in donating a kidney or in donating bone marrow and what benefits might there be?

In the first place, I will generate an estimate of the rate of complication (both morbidity and mortality) associated with the use of general anæsthetic —a risk that the donor will be subject to in either bone marrow or kidney donation. The focus will then shift to a review of the risks attending bone marrow harvesting. Clearly, while the risks of bone marrow donation are not negligible, they are less severe than those involved in renal donation; this is because the procedure is less invasive than renal donation, consisting of repeated needle aspirations under general anæsthetic, and because bone marrow, unlike a kidney, is regenerated upon depletion. The review of the risks associated with kidney donation will be more complicated because of the potential severity of the risks. I will address three principal questions: (*i*) What is the nature, and the rate, of peri- and post-operative complications associated with the removal of a kidney from the healthy transplant donor? (*ii*) What are the consequences of, and risks associated with, living one's life with only one kidney? and (*iii*) What are the possible psychological benefits and burdens associated with kidney donation? The results of the third question will, to an extent at least, hold true for the bone marrow donor as well as the kidney donor.

In chapter 3, the focus will be the legal response to kidney donations by children and incompetent persons. Because the courts have shaped the way we think about this issue, it will be important to first understand their thinking about the matter before we move on in the next chapter to assess the worth of the standard account they have proffered. The purpose of the chapter is not to offer a comprehensive exegesis of all of the legal sources dealing with minor and incompetent donation. Rather, the focus is restricted to the common law since the aim of the chapter is to present the way in which the courts have thought about this issue as a primer for the ethical analysis to follow in chapter 4. The question to be addressed, therefore, is: what has been the position of the courts, both procedurally and substantively, with respect to the issue of using incompetent persons or children as the source of organs for transplantation? A review of the major reported United States transplantation cases will be undertaken in order to determine the decisionmaking framework of the courts and the reasoning employed by the courts.

Two major decisionmaking frameworks emerge: the doctrine of substituted judgement, and the best interests standard. Both will be subject to critique. Beginning with the first unreported declaratory judgements in Massachusetts in 1957 the chapter will highlight the extent to which the courts have relied upon the best interests standard when passing their judgements, and it will show that the courts have used a rather broad version of the best interests standard in their deliberations, one that makes psychological benefit its focus. A provisional conclusion of the chapter will be that the courts, confronted by their traditional role as protectors of children but recognizing the enormous good that they could do in authorizing the donation, fashioned a solution to this problem by interpreting the best interests standard as broadly as possible. Unfortunately, as will be shown, this broad interpretation sometimes led the courts (in the earlier years, at least) to rule foolishly. I will track the evolution of the best interests standard through over 30 years of jurisprudence ending with the 1990 case in Illinois of an attempt to compel twin 3½ year-olds to donate bone marrow to their dying half-brother.

The ethical discussion in the final chapter is informed by the case law discussed in chapter 3. In chapter 4, I will attempt to offer an answer to the following question: is it ever morally permissible to use a minor child as a tissue or organ donor for the benefit of a family member, and if so, on what grounds is it permissible? After outlining the preconditions for considering the use of the child as a donor, the chapter will move on to examine and critique the best interests standard both as expressed in the common law judgements of chapter 3, and as expressed in the bioethics literature. An argument will be made to the effect that not only is the standard understanding of "interests" too narrow but the best interests standard itself may not be the appropriate decisionmaking framework for this problem at all.

The remainder of the chapter will be constructive in intent and will situate this problem squarely within the family. After offering an account of the foundations of parental authority as one based on intimacy, the focus will then turn to parental decisionmaking authority and its scope. Although parents should not have absolute authority over their children, neither should they be bound to act only in the strictly calculated best interests of their child. Once the importance of the family to its members is articulated, the moral landscape should be altered; unlike the abstractness, individuality and impartiality that characterizes the best interests standard, families are concrete, collective and partial associations where different interests are at play — family interests, as they will be called.

The chapter concludes that the strongly valued commitments observed within families may allow parents to subject a child to greater burdens than a strict best interests calculation would allow for. I then examine what this might mean in the concrete cases of organ and tissue donation. At this point in the argument, the importance of chapter 2 will be apparent; for although the chapter argues for broad parental authority, I express some reservations about the permissibility of using uncomprehending minors for the purpose of kidney donation due largely to a recognition of the risks to which the donor is exposed.

Endnotes

1. Mature minors and emancipated minors fall outside of the analysis presented here. On this see: chapter 4, *infra*, note 72.

2. The reasons for this are explained in chapter 2, *infra*, **§2.3 Bone Marrow Donation**.

3. McEnery PT, Stablein DM, Arbus G, Tejani A. Renal transplantation in children - A report of the North American Pediatric Renal Transplant Cooperative Study. *N Engl J Med* 1992;326(26):1727-32. This review of 1550 children and 1667 renal allograft operations between 1987 and 1990 showed a marked difference in graft survival rates between children who received their kidneys from living related donors or cadaver donors. The one-year graft survival rates for living related versus cadaver donations were, 89% *vs.* 74%, while the three-year graft survival rates were, respectively, 80% *vs.* 62% ($P<0.001$). The differential in graft survival rates (live donors *vs.* cadaver donors) in the population of adult recipients is far less marked than that found in the pædiatric population.

Chapter 2:

Risk Identification and Estimation of Bone Marrow and Kidney Donation

§2.1 Introduction

It is perhaps a truism to claim that living life is not without risk[1] — everyday activities of everyday people involve various degrees of risk to one's health: eating, drinking, driving one's automobile, riding the bus, having sex, sunbathing, and worrying all have implications for one's health. This fact has been captured in a well known bumper sticker that reads: "Life is hazardous to your health."[2] Risk, so conventional wisdom has it, is additive; risk, in other words, is something 'added on' to one's daily life, and is an aspect of one's life that can (often) be eliminated. Contrary to this view, however, it is perhaps less obvious to recognize that risks are partially substitutive[3]; foregoing an activity, or reducing the risk in an activity, will often entail an increased risk in another activity: wearing a safety belt will reduce my risk of dying in an automobile accident, but in thus living longer, I expose myself to a higher risk of developing cancer brought on by age, the single greatest risk factor for cancer.[4]

In the context of bone marrow or kidney donation by minors, the parents of a prospective child donor would be deciding based on only half of the relevant information if they made their decision about whether their child could act as a donor based on the risks alone, even a more subtle view of risks as being partially substitutive. Rather, parents must also examine the potential benefits that can accrue to their child as a result of his or her participation as a tissue or organ donor if they are to choose responsibly. The purpose of this second chapter, then, will be to assess the probable risks, the possible benefits and the associated discomforts to the donor that may accrue as a result of the donation of a kidney or of bone marrow. Following Nicholson[5], the process of risk assessment can be divided up into three components: (*i*) risk identification — a qualitative description of the risks involved (*e.g.*, the magnitude of the risks); (*ii*) risk estimation — a quantitative description of the risks involved (*e.g.*, the probability that the adverse event will occur); and (*iii*) risk evaluation — a determination of whether or not the risks are acceptable given the familial context in which the donation takes place.[6] In what follows, components (*i*) and (*ii*) will be presented, while component (*iii*) of the risk assessment process, *modulo* certain adjustments, will be left for chapter 4.

Given this framework, in §2.2 we will first attempt to determine the approximate rate of complication (morbidities and mortalities) that is associated with the use of anæsthetic in general surgical procedures. To this end, the results of the few large studies available in the literature will be presented. Our next task in §2.3 will be that of examining and assessing the risks and benefits associated with the procedure of bone marrow extraction. Here, we will offer a survey of the literature, sparse as it is, related to the risks and benefits involved in donating bone marrow. Finally, in §2.4 we will present a comprehensive review of the literature relating to kidney transplant donors in the attempt to answer the following questions:

- What is the nature, and the rate, of peri- and post-operative complications associated with the removal of a kidney from the healthy transplant donor?

and,

- What are the consequences of, and risks associated with, living one's life with only one kidney?

This fourth section of chapter 2 will be more involved than the two sections preceding it for two reasons. Because of the potentially serious risks that can attend kidney extraction surgery, many doubts have been raised regarding the prudence of performing this procedure on healthy subjects; accordingly, there exists a vast literature which addresses the two questions I posed above and one which demands more attention than the literature discussed in the previous two sections. Moreover, and more importantly, given the potentially serious nature of the risks associated with kidney extraction, we will want to invest more time in determining what *exactly* are the risks to the prospective kidney donor.

§2.2 Anæsthetic

On 3 July 1842, the first pædiatric anæsthetic was administered to an 8 y-old boy who was to have his toe amputated. The child recovered with no recollections of the experience and with no post-operative pain; preliminary evidence regarding the safety and efficacy of pædiatric anaesthesia was thus established. Six years later, a 15 y-old girl undergoing toenail excision under anæsthetic, provided the world with a tragic counterpoint to the earlier successes of pædiatric anaesthesia: the first recorded anæsthetic death brought with it the recognition that anæsthesia carries medical risk.[7] Although serious adverse events due to anæsthetics are rare, anæsthetic risk remains the first class of risk that the medical team and the family of the child usually consider. In order to address this issue, a review of the literature was conducted (medline) and articles (post-1980) that turned up under several combinations of the search terms were chosen for descriptive analysis.

§2.2.1 Risks. Mortality in the general surgical population (adult) caused totally by anæsthetic has been the subject of much study. Mortality rates have been estimated variously as: 1 per 10 000 anæsthetics (0.01%)[8]; 1 per 185 000 anæsthetics (0.0005%)[9]; or 1 per 13 207 anæsthetics (0.008%)[10]. The most recent study to address this issue specifically in the pædiatric population (1 y-old < *age* < 15 yrs-old) has turned out a mortality risk estimate of 1 per 38 137 anæsthetics (0.003%).[11] According to these estimates, in both adult and pædiatric populations, mortality due to anæsthetic remains a rare event.

Not surprisingly, however, there are various morbidities and discomforts associated with anæsthetic use. These include, but are not limited to: aspiration (inhaling of gastric contents), cardiac arrest, arrhythmia (irregular heart rate), malignant hyperthermia (an acute hypermetabolic reaction to anæsthetic characterized by increased heartbeat and respiration, unstable blood pressure, increased blood-CO_2 levels, and highly elevated body temperature), Masseter muscle spasm (isolated contracture of the jaw muscles) and dental injuries, hypoxia (low blood-O_2 levels), laryngospasm, bronchospasm, prolonged paralysis, anæsthetic overdose and coma, respiratory infections, and most frequently, postoperative nausea and vomiting.[12]

Three follow-up studies dealing with pædiatric populations were reviewed; taken together, they report on the administration of over 267 500 anæsthetics. In the largest study, Tiret *et al* report that in their population aged 1-14 years old, there was a complication rate of 1 per 2500 anæsthetics (0.04%) due partially or totally to the anæsthetic. The population aged 1-14 years old were at the lowest risk for complication in their series.[13] The same authors in a later study, report that 18 major complications occurred in 38 137 anæsthetics, for a risk of anæsthetic morbidity of 0.05%.[14] Finally, Cohen *et al*[15] in their review of 29 220 anæsthetic administrations, found that the risk of *any* complication ('minor' or 'major', intraoperative, recovery-room, or postoperative) was 39%, while the risk of a major complication was 3.3%. In this series, approximately 70% of all complications were accounted for by nausea, vomiting, croup, sore throat, headache and muscular pain — complications that were not insignificant, but were nonetheless minor.[16]

§2.2.2 Discussion. It should be clear from the few results presented above that the risk of mortality and morbidity due partially or totally to anæsthetic in pædiatric populations is slight, with the greatest proportion of complications being of a minor and transient nature. It has been established that the risk associated with anæsthetic use is directly proportional to the length of the procedure during which the patient is under the influence of the anæsthetic; for this reason, anæsthetic risk will be higher for the kidney donor than for the bone marrow donor. However, all of the authors surveyed stress that the most reliable predictor of outcome in procedures that use anæsthetics is the patient's preoperative condition; the population of patients who were disease-free preoperatively had the lowest risk of suffering any complications. Consequently, the results presented above may overestimate the risks to the bone marrow or kidney donor because, presumably, unlike almost all of the patients in these series, donors (especially child donors) are virtually always healthy and free of any comorbidities. It seems, then, that the risks attending general anæsthetic administration are slim, although not negligible.[17]

§2.3 Bone Marrow Donation

Initially used in the late 1960*s* as a treatment for certain immunodeficiency diseases, bone marrow transplantation is today an essential component in the treatment of a variety of hæmatological malignancies (especially the childhood leukæmias), immunodeficiency diseases, certain metabolic disorders, inherited blood disorders, as well as other neoplastic diseases.[18] Bone marrow, the soft inner core of one's bones, is composed of a population of hæmatopoietic — literally, 'blood making' — stem cells that give rise to the cellular components of the blood and to the cells of the immune system. Often, however, the marrow of a patient is, or can become, defective and therapy must be initiated to ameliorate this condition. The purpose of bone marrow transplantation then, is to (*i*) replace malignant or genetically defective hæmatopoietic stem cells with healthy, functional stem cell; (*ii*) replace the hæmatopoietic stem cells incidentally destroyed by high-dose chemotherapy and/or radiation intended for the malignant cells; and (*iii*) for certain cancers, provide the body with a source of immunocompetent cells that will destroy any residual malignant cell — the so-called graft *vs.* leukæmia effect.[19]

When bone marrow transplantation was first conducted in laboratory mice, researchers quickly discovered that mice receiving transplants from genetically identical mice survived longer than those whose donor mice were non-identical.[20] Today, despite the advances that have been made in immunosuppressive pharmacology, an identical twin sibling will ensure the best clinical outcome for the recipient.[21] The next best results, however, are achieved by *immunogenetically* identical siblings; the term 'immunogenetically identical' means that two individuals carry identical genes at a region on the short arm of chromosome 6 called the Major Histocompatibility Complex (MHC).[22] The human MHC contains a series of genes that encode two distinct classes of highly polymorphic cell surface molecules, called human leukocyte antigens (HLAs), that bind and present antigens to approaching T lymphocytes (killer cells). The proteins encoded by the HLA loci are located on the outer surface of cells and effectively act as an 'identity card' so that the body's immune system will recognize cells bearing this antigen as 'self', as opposed to 'foreign'; without these surface antigens, the body's immune system would attack its own body, leading to the death of the individual.

Given that the immune system of the recipient is of donor origin, then, the recipient must undergo a preparatory regimen which is designed to eliminate the progenitor and mature cells of the recipient's own immune system in order to ensure that the 'foreign' bone marrow is not immunologically rejected. Despite this preparatory regimen, many of the recipient's immune cells survive and the marrow graft is rejected. The best results, then, in order of decreasing effectiveness, are achieved when the donors are: identical twins, HLA-identical siblings, HLA-matched unrelated donors, and finally, HLA-mismatched unrelated donors, of which there are various degrees of mismatch.[23] Because of the way in which one's HLA genes are inherited, there will be a 1 in 4 chance that any sibling of an individual in need of a bone marrow transplant will be HLA-identical; *i.e.*, there is a 1 in 2 chance that *each* of the mother and father passed on the same haplotypes to any child. Estimates suggest, however, that about 30% of patients in need of a marrow transplant have an HLA-identical sibling.[24]

For the purposes of this section, one should note simply that a closely matched family member, most often a sibling, will provide the recipient with the greatest chance that the bone marrow transplant will successfully engraft, and thus with the greatest chance that the recipient will be cured of her disease. Given this fact, the task at hand is to identify and estimate the risk to which a marrow donor is subject during marrow harvesting.

§2.3.1 Risks to the donor. The extraction of bone marrow from the donor is, from a technical point of view, a relatively easy surgical procedure. The patient, under general anæsthetic, is placed prone on the operating table in a manner that makes the posterior iliac crests (part of the 'hip bone') prominent. Once the patient is so situated, marrow extraction proceeds via repeated (often, up to 200) needle puncture and aspirations of the iliac crests with a large bore needle; if an insufficient yield of nucleated cells in the aspirate is obtained from the posterior iliac crests, the anterior crests and sternum will be aspirated as well. Whether or not both posterior and anterior iliac crests are aspirated will affect the length of the procedure: in a series of 1549 marrow extractions between 1983 and 1990, the median time for the procedure was 75 minutes with a range of between 10 minutes and 205 minutes.[25] The volume of marrow extracted varies (approximately 750 mL)[26], but this volume is replaced by packed red blood cells and the marrow is thereby quickly regenerated by the donor.[27] The majority of donors are discharged from hospital within 24 to 36 hours of donation, while many transplant centres now perform marrow extraction on an outpatient basis.

Marrow donation, however, is not without risk. In a follow-up study of 236 marrow donations, Filshie *et al*[28] report that the most serious complication encountered in their series was one patient who experienced severe headaches and vomiting post-donation, both of which were likely caused by the exposure to anæsthesia. Less serious morbidities reported by the authors were 8 donors who had short-lived fever, and less than 10% of the donors who experienced either nausea or vomiting post-operatively.

C.D. Buckner and colleagues have reported on 4 studies of bone marrow donors that collectively followed up 7534 adult donors.[29] In these 4 studies, the authors count 21 instances (0.28%) of life-threatening complications that included cardiopulmonary arrest, pulmonary embolism, carotid artery occlusion, ventricular tachycardia (a very high heart rate), bacterial infection at the aspiration site, bleeding that required several transfusions (receiving blood products is considered to be a risk factor for disease transmission such as HIV and Hepatitis), and excessive iliac pain. The authors note that most of these life-threatening complications (as well as most major complications) could be attributed either to the poor pre-operative health of the donor, or to the use of anæsthetic. Among the less severe complications encountered by the patients in their series were bleeding that required one transfusion, post-aspiration fever, nausea, vomiting, headache, and general post-operative weakness that required hospitalization. Considered collectively, the risk of complication in over 7500 marrow donors was in the 15% to 25% range, with the majority of complications considered minor.

It is noteworthy that psychological morbidities or burdens were not mentioned in any of the studies under review above. Unlike the case of renal donation, where the donor can reasonably worry about the consequences of having lost a *non-regenerable* organ (see *infra*, §2.4.1.3.), the bone marrow donor undergoes a less invasive procedure and gives up *regenerable* tissue. It is plausible, then, that the bone marrow donor is unlikely to suffer some of the psychological trauma associated with concerns about bodily integrity and/or physical health as can occur in renal donors; or, perhaps the psychological trauma will occur but will be far less severe in magnitude (however defined). The lack of formal study of this issue attests, in part, to the plausibility of this suggestion.

On the other hand, however, there is a sense in which the bone marrow donor may find himself at increased risk of psychological trauma as compared to the kidney donor. When a kidney graft is rejected, the recipient has a therapeutic option: hæmodialysis, followed by another kidney transplant, if possible. As such, the donor need not feel that she is the recipient's 'last hope.' In the case of the rejected marrow graft, however, the recipient faces a far bleaker future: second bone marrow transplants are notoriously unsuccessful.[30] Given this clinical reality, then, the marrow donor can feel a heightened sense of responsibility for the outcome: "He or she seems to feel fused psychologically with the recipient so that the perception is no longer 'the transplant failed,' but rather 'I (the *me* inside my sibling) failed.'"[31]

§2.3.2. Benefits to the donor. Not surprisingly, the donor of bone marrow does not stand to receive any physical benefits from her donation; she is, however, likely to received what may be termed psychological benefit as a result of her attempt to save the life of a loved one. Largely as a result of the relatively safe nature of bone marrow donation, there has been very little formal study of the psychological impact of donation on the donor. This stands in contrast to the vast literature which addresses this question in the case of renal donors; the reader is referred to these sections (§§2.4.1.3-2.4.2, *infra*), because the issues discussed are largely the same.

One should be mindful of the following proviso, however. Given that marrow donors can often be very young, there are reasonable grounds to believe that the younger donors may not receive the psychological benefits that older donors might receive until later in life. For, presumably, a donor of a kidney or of bone marrow will benefit, or will stand to benefit, psychologically to the extent that she has an understanding of the situation in all its complexity: that a family member is dying, that she will be instrumental in saving, or attempting to save, the patient's life, that she herself is subject to risk, that she is playing an important role in the treatment of a loved one that she perhaps would not do for a stranger, *etc.* Thus, it is unproblematic to claim that the youngest recorded donor — a 7 week-old girl[32] — or infant donors generally[33], will have no chance of receiving psychological benefit until such time, many years later, as they are old enough to understand what transpired. The point is that psychological benefits dubiously accrue to those who have insufficient intellectual capacity.

§2.3.3. Discussion. The procedure of bone marrow harvesting carries only slight risks to the donor, with most of the morbidity being minor and accounted for by pain at the iliac crests and post-operative nausea and vomiting. Major complications are rare and can usually be accounted for by the poor pre-operative health of the donor — such poor pre-operative physical status would, one imagines, be rather rare in child and adolescent donors. Finally, in the nearly 7800 marrow donations reviewed above, 99.72% proceeded without any life-threatening risk to the donors. In light of the slight physical risks to which the marrow donor must submit, and given that there are potential psychological benefits to be gained for the older donors, the marrow donor is faced with a reasonable risk/benefit ratio without having to consider the enormous (potential) benefit the recipient stands to gain. Countervailing concerns center on the psychological burdens associated with donating one's bone marrow, and should be kept in mind.

§2.4 Kidney donation

Approximately fifty years ago, the patient whose kidneys were diseased faced a grim future; hæmodialysis —the filtration and purification of blood by an 'artificial' external kidney— was the only feasible therapeutic option, and was one which brought little long-term benefit to the patient. Originally used as a treatment for acute kidney trauma in the late 1940*s* and 1950*s*, hæmodialysis soon became an accepted treatment modality for those patients who suffered from chronic kidney failure. There was, however, great concern in the medical community regarding the use of hæmodialysis in chronically ill patients. Although well suited to perform the functions of the kidney for a short time while the patient's own kidneys healed, the artificial kidney could do nothing to ameliorate the condition of a patient who suffered from chronic, progressive renal disease. Francis Moore, a pioneering transplant surgeon in the 1950*s*, commented that "[a] patient with chronic kidney failure might be kept alive for weeks, months, or years, but he had little to look forward to if his own kidneys could not be replaced."[34]

A new therapeutic vista was opened late in 1954, however, when a successful kidney transplant operation between 24 y-old identical (monozygotic) twins was performed.[35] Up to and until 1954, insufficient technical know-how in overcoming the problems posed by tissue incompatibility had prevented the successful transplantation of solid organs between humans; newly transplanted kidneys continued to be attacked by the recipient's immune system leading to the rejection of the graft and often, to the death of the recipient. To be sure, the kidney transplantation in Boston was a huge success and one which proved to be of key importance in changing the clinical landscape, but Merrill and colleagues concluded their case report on a sober note: "Tissue transplantation including that of a functioning kidney appears to be a feasible procedure in identical twins, but to date successful permanently functioning homografts appear to be limited to such individuals."[36]

The progress in knowledge of transplant immunology, along with parallel developments in pharmacological immunosuppressive regimens in the early 1960*s* (azathioprine and prednisone), in the early 1980*s* (cyclosporine A), and in the 1990*s* (FK 506) has made renal transplantation a reasonably safe and effective therapeutic option for those patients who require renal replacement therapy — regular dialysis treatment or renal allografting.[37] Despite the pharmacological advances that have been made, the best clinical outcome for the recipient of a renal allograft obtains when the donor is an identical twin. The immunogenetic and cellular reasons behind this are as discussed above in §2.3, with one significant difference. Unlike the case of bone marrow transplantation, where the immune system of the recipient is that of the donor, in renal donation the immune system of the recipient remains of host origin. As such, the recipient's immune system will, unless pharmacologically suppressed, attack the foreign kidney, ultimately leading to the rejection of the graft. If, however, the donor is an identical sibling, this problem is by-passed.

Obviously, however, those who develop some kind of end-stage renal disease (ESRD) will rarely have a willing identical twin from whom one can harvest a kidney. Given this fact, and given the fact that kidney demand far exceeds kidney supply, there has been a widespread attempt by various means — donation notification on driver's licenses, mandated consent schemes, increased public awareness, to name a few — to increase the pool of potential donors to include living-related, living-unrelated and cadaver donors. And although the supply of organs for donation has certainly increased as a result of these mechanisms, the majority of patients with ESRD will find themselves without access to a suitably matched cadaveric kidney.[38]

The relative lack of suitably matched cadaveric kidneys, coupled with the better prognosis obtained when using a kidney from a living-related donor has made the living relative the *medically* preferred donor although there is widespread reluctance in the medical community to the use of such living-related donors. Given that the living related donor stands to receive no medical benefit from the procedure and is subject to *potentially* serious harms by being nephrectomized, it is often felt that the slightly poorer prognosis that is achievable using cadaveric kidneys is to be preferred to the better prognosis of using live related donors given the attending harms that can befall such donors. One commentator put it this way:

> ...I believe that everyone who performs living donor

> transplants looks forward to the day when this procedure will be of historic interest only. That day is not upon us because, first, the risks to the donor are minimal; second, the supply of organs is inadequate; and third, the results of cadaver donor grafts are not comparable to those that are obtained now with living donor grafts.[39]

Given the importance of ascertaining the risk to potential donors, then, and given the vast literature that has examined this issue, it is therefore surprising that no one has undertaken a comprehensive review of this literature, one which addresses both peri- and post-operative complication rates and long-term consequences related to the hyperperfusion in the remnant kidney. This is the purpose of the following section.

§2.4.1 Risks to the donor. In this section I will report on three separate bodies of research; one that deals with peri- and post-operative risks attending the kidney donor, another that focuses on changes that occur to the remnant kidney under the stress of hyperperfusion (the increased filtration rate in the remaining kidney as it must filter what previously was filtered by two kidneys), and the last that is concerned with the psychological sequelae attending organ donation. We will examine these issue in turn.

§2.4.1.1 Peri- and post-operative risks. The results of 7 follow-up studies published between 1972 and 1988 are presented. An examination of the data will reveal that there are many methodological differences between these studies (*e.g.*, years of follow-up, operational definition of 'peri-operative' and 'post-operative', sample size, *etc.*) that limits our ability to compare them in a systematic manner. We can nonetheless discern similarities in the results that will be of importance to the broad aims of this chapter.

First, in the over 1400 patients (pooled) that were followed in the 7 studies, there were no mortalities associated with uninephrectomy. Others have reported on the mortality rate associated with donor nephrectomy variously as: 0.06% as of 1973 (1 donor death in 1565 kidney extractions)[40]; 0.09% as of 1975 (no further information given)[41]; 0.02% as of 1981 (4 deaths in 20 000 worldwide living donor transplants)[42]; and 0.06% as of 1984 (5 deaths in 8193 kidney extractions in the U.S.)[43]. Taking the weighted average[44] of these risk estimates yields an overall mortality rate of slightly more than 0.03%; put differently, the mortality rate associated with donating one's kidney is approximately 1 death per 3000 donors. One of the most recent studies which reports on the North American mortality rate associated with elective kidney extraction (up to 1991) cites a figure of 17 peri-operative deaths in approximately 57 000 live donor nephrectomies —a risk of 0.03%, or approximately 1 death per 3350 donors.[45]

The different methods used in these 7 studies limits our ability to compare the results systematically, but we can report the results in the following way. We can pool the results of those studies that individually followed the same number of patients throughout their evaluation of peri- and post-operative complication rates (this would include the 2 studies that made no distinction between peri- and postoperative complications). As such, pooling the results of 5 studies[46], we find a weighted mean complication rate of 40%. In the 2 remaining studies[47] where the number of patients in each study followed during the post-operative period was a subset of those followed during the peri-operative period, we find a mean peri-operative complication rate of 34% and a mean post-operative complication rate of 28%. Thus, from the reports under study we could estimate that the rate at which kidney donors suffer complications, whether minor or major, is approximately 30% to 40%.

Among the most frequent complications that occurred in the 1404 donor nephrectomies were, in order of decreasing frequency: atelectasis (collapse of a small portion of the lungs), urinary tract infection (due to the urinary catheter), pain (most frequently at the site of the incision), hypertension (usually mild and transient), blood loss during surgery requiring transfusion, wound infection, incisional hernia, and pneumonia. In almost all instances these complications were of a minor and transient nature.

There were, however, serious complications which were associated with donor nephrectomy. The most serious of which were: three cases of pancreatitis[48]; a 57 y-old female with a pulmonary embolus[49]; 2 donors who developed hepatitis 2 and 3 months post-nephrectomy, respectively[50]; 2 cases of psychiatric breakdown in donors who, it should be noted, both had previous histories of mental problems[51]; 5 cases of splenectomy (surgical removal of spleen) necessitated when the spleen was accidentally torn during kidney extraction[52]; 3 cases of adrenalectomy (surgical removal of adrenal gland) when the adrenal gland (situated immediately anterior to the kidney) adhered to the kidney during extraction[53]; 2 cases of tracheostomy (a surgical procedure to make an opening in the trachea in order to reinitiate spontaneous breathing) when the trachea ('windpipe') of these patients collapsed[54]; and 5 cases of bowel obstruction necessitating laparotomy (a surgical opening in the peritoneal cavity) and lysis (dissolution) of the obstruction[55]. In all of these cases, the patients recovered and returned to their previously normal lives with minimal delay.

§2.4.1.2 Long-term risks to kidney function. A second but equally important concern with which we must deal involves an assessment of the long-term risk posed to the donor by uninephrectomy and the subsequent hyperperfusion of the remnant kidney. By 'long-term', we mean anywhere from a few years post-nephrectomy to 6 or 7 decades post-nephrectomy — in effect, until the donor passes away.

It is well-known that reduction in renal mass alters renal hæmodynamics significantly; when one kidney is removed, the other kidney must filter more blood than it would were it paired with another kidney. This sustained renal hyperperfusion may have detrimental consequences for the donor. First, it has been shown that sustained renal hyperperfusion leads to renal hypertension, which in turn will bring about increased protein filtration (evidenced by proteinuria — *i.e.*, protein in the urine) and which may initiate glomerular sclerosis.[56] Ultimately what will happen to the kidney when placed under such increased hæmodynamic load is that the total population of nephrons will progressively die out and the patient will suffer from ESRD necessitating renal replacement therapy. Second, however, renal hypertension has been implicated as a probable cause of *systemic* hypertension in human populations with decreased renal masses.[57] Simply put, there is evidence in the literature to suggest that a decreased renal mass is a risk factor for systemic hypertension, proteinuria and progressive renal failure.

A literature review was conducted (medline) and 12 studies[58] published between 1978 and 1994 were chosen for descriptive review. Pooled, the studies followed 1173 kidney donors with a (weighted) mean age at donation of 37.4 years, for a mean follow-up period of between 5.3 years and 14.6 years. In most but not all of the studies, the clinical parameters examined were: (*i*) hypertension, (*ii*) proteinuria, and (*iii*) renal function (*via* serum creatinine levels, and/or creatinine clearance[59]). The prevalence of new cases of hypertension (*i.e.*, where patients were normotensive pre-nephrectomy) in these studies ranged from 0% to 47.4%, with 6 out of 9 studies reporting a prevalence of less than 11%. It is worth noting that in none of the 12 studies was there found to be a statistically significant difference in the prevalence of hypertension among kidney donors and the chosen reference population (age and sex matched controls from the community, or the siblings of the donors).

Among the 1173 donors who were followed, slight increases in urinary protein levels were found in between 2.9% and 50% of the cases. In all cases, the proteinuria was considered mild and of unknown clinical importance.[60] Moreover, in none of the studies that employed age and sex matched controls[61] was there a statistically significant difference between donors and controls. Renal function, similarly, although found to decrease to between approximately 65% and 80% of pre-nephrectomy levels, was considered to be both stable and satisfactory.[62]

Finally, there have been studies that examine the same clinical parameters as the 12 studies discussed above (hypertension, proteinuria, and renal function) in different but, for our purposes, relevant populations. Unlike the studies examined above, these populations —largely patients with renal agenesis (a problem of early development where only one kidney develops), some form of unilateral kidney disease, or those who suffered a unilateral renal trauma early in life— are much younger at the time of the renal insult than adult renal donors and they must bear the burden of functioning with only one kidney for far longer than adult renal donors (6 or 7 decades in the former case, and 3 or 4 decades in the latter). In 5 follow-up studies carried out on these alternative populations up to 50 years post-nephrectomy, it was found that the 3 clinical parameters of interest were all within normal ranges, and that there was no increased mortality associated with having only one kidney.[63]

Thus, according to the studies that have been reported on here, it appears that long-term renal function is well-preserved in patients who undergo elective nephrectomy for the purposes of transplantation, as well as among those patients who are either nephrectomized early in life due to unilateral kidney disease or born with only one functional kidney.[64]

§2.4.1.3 Psychological risks. Often neglected when considering the risks of organ donation, psychological burdens — or, perhaps more accurately, potential psychological burdens — due to donation must be ascertained when discussing the permissibility of organ donation. Simmons and colleagues, pioneers in the research into the social implications of organ donation, have highlighted the importance of the psychological aspects of organ donation: "The central ethical issue here is whether the psychological costs to the donor are too great to recommend related donation."[65] Thus, in what follows we will be looking at 9 studies that examine the issue of psychological costs associated with living related renal donation.[66]

One of the first studies to examine the question of whether or not kidney donation was associated with any psychological sequelae, Kemph[67], in a study of only 7 donors, reported that donors often felt depressed and unrewarded after donation. All 7 donors, Kemph found, had "unconscious resentment" toward the recipient and the hospital staff because they had "given something up and got nothing in return"; such feelings of resentment were often exacerbated by the fact that the donors had felt coerced into their decision. Moreover, as Kemph notes, 2 female donors confounded their kidneys with their reproductive organs and experienced anxiety about possibly diminished childbearing potential as a result of the procedure —a mental reaction Kemph described as being "equivalent to castration."

In stark contrast to Kemph's observations, the remaining 8 follow-up studies under review here which followed a total of 1340 kidney donors for a mean follow-up period of between 1.7 and 7.3 years, found that there were very few psychological or psychiatric morbidities associated with elective nephrectomy.[68] In the 4 studies that reported the age of the donors at nephrectomy[69], the mean age range was between 17.8 and 58.5 years. In all cases, the donors were subject to either quality of life questionnaires, or to psychiatric/psychological interviews using a variety of instruments. However, as a result of the different instruments used to assess psychological well-being in the donors, our ability to compare the results of these studies systematically is rendered problematic. We will, consequently, briefly list the psychological morbidities that were discovered in these studies.

Fellner and Marshall, in their study of 20 donors, found that 1 patient (5%) experienced nausea and depression for one week post-nephrectomy, 1 patient (5%) felt homesick for 3 days post-nephrectomy, while another patient (5%) had an acute panic attack when, several days after the operation, he realized what could have gone wrong.[70] Bernstein and Simmons found that only 1 patient (out of 18 –6%) had a negative reaction to the procedure: the donor became acutely anxious one month after nephrectomy because she worried that her remaining kidney might be diseased; her anxiety was short-lived.[71] Simmons, Klein and Simmons, in their 1 year follow-up of 111 donors, report that only 1 donor (1%) said she was uncertain as to whether or not she would donate again (hypothetically), while another 2 donors (2%) indicated that they were "unhappy" about having donated, and 5 donors (5%) expressed regret at having given something of themselves and having received nothing in return. Additionally, the authors report that 7 donors (6%) felt badly because their relationship with the recipient had become difficult as a result of the transplant.[72]

Simmons and Anderson, who followed 135 donors, report that 38 donors (28%) reported a decrease in self-esteem after donating their kidney. In addition to this, they performed subgroup analyses on this population on the basis of whether the graft had been accepted or rejected by the recipient (the authors refer to the former group as 'successful donors', while the latter are referred to as 'unsuccessful donors'). They found that 6 of the 50 unsuccessful donors (12%) regretted that they had donated, while this was found in 7 of the 85 successful donors (8%) —a difference which did not reach statistical significance. Moreover, they report that among unsuccessful donors, 9 (18%) felt that their relationship with the recipient had worsened post-donation, while only 7 of the successful donors (8%) reported experiencing such a decline in the relationship with their recipient —this difference was statistically significant.[73]

The largest study reported on here, that of Smith *et al.*, found that only 8 of 536 donors (1.5%) found that their relationship with the recipient had become worse as a result of the donation, and that 2 (0.4%) regretted their decision and would not do it again.[74] Sharma and Enoch, in a much smaller study of 14 donors, determined that only 2 patients had negative psychiatric sequelae following donation; both of these patients, it turns out, had previous (pre-donation) histories of depression and anxiety. Interestingly, however, they found that 1 donor had strong feelings of resentment towards his brother (the recipient) claiming: "I felt neglected after the operation was over. My brother got all the publicity and I was left on my own. I hated him, I wished he was dead." Although the donor was estranged from his brother for 4 years, they reconciled thereafter.[75]

Morris *et al.* report that 5 out of 12 donors (33%) experienced some form of negative psychosocial sequelae following the donation of their kidney. As the authors themselves acknowledge, 4 of the patients had poor social support structures and it is unclear what role the donation experience played in their psychological problems.[76] Finally, in a study that measured 19 aspects of quality of life among 494 donors and 74 977 members of the general public, the most negative result that Westlie *et al.* report is that unsuccessful donors had a quality of life equal to, but no less than, that found in the general population.[77]

Considering the 8 studies collectively, among 1340 living related donors the authors report that 88 patients developed negative psychological sequelae post-nephrectomy, almost all of which were minor in nature, for a cumulative risk of 6.6%. Undoubtedly, donating one's kidney to a family member is, even in the most supportive environment, a highly emotional and psychologically taxing experience. Even when the donation proceeds as well as it possibly could, there will nonetheless be many psychological burdens placed on the donor; these burdens will, moreover, often be of a kind previously unfamiliar to the donor. Thus, although the risk of psychological morbidity was found to be quite low in this series, the fact remains that organ donation will alter family dynamics, often beyond recognition: "The life-or-death circumstances that surround [live organ donation] and the extraordinary gift it entails bring to the surface the structural strengths and weaknesses of a family and the collective life history in which they have been played out."[78] Recognition of the inherently stressful nature of organ donation should be kept in mind when evaluating the risk of live organ donation.

§2.4.2. Benefits to the donor. An evaluation of the risks of a medical procedure is meaningful to decisionmaking only when viewed against the background of, *inter alia*, an evaluation of the benefits of that medical procedure. The standard argument of those who oppose the use of live kidney donors centres on the unfavourable risk/benefit ratio of kidney extraction: unlike therapeutic interventions, so the argument goes, organ and tissue donors are placed at an increased risk with no prospect of benefit to be gained. J.S.Najarian, a prominent kidney transplant surgeon, has claimed that "Living-donor organ donation is the only operation with no planned benefit to that patient."[79]

Such arguments are premised on an overly narrow interpretation of the concept of 'benefit'; the concept of benefit, itself relatively clear and meaning roughly 'increased well-being', is made intelligible via different conceptions of benefit. Most commentators have wrongly focused on the physical conception of benefit (*e.g.*, medical gains) to the exclusion of the psychological conception: 'What possible benefit could a person gain from having his healthy kidney removed?' is a question not unreasonably posed, but one which highlights this narrow interpretation of 'benefit'.

I would like, in what follows, to engage a broader understanding of benefit, one that includes psychological components. As illustrated in §2.4.1.3, there is a cluster of negative psychological conditions which might develop in the kidney donor post-nephrectomy; there is, however, real benefit that may accrue to the organ donor as a result of her experience. In a rather discursive manner, I will discuss such benefits in that which follows.

I intend to discuss the studies that formed the core of the analysis above in §2.4.1.3, and focus on two classes of benefit which generally emerge in some of the research under review: one class of benefit relates to the self-perception of the donor post-donation (almost always regardless of the donation outcome), and we might say that this evidences some form of intrinsic good of donation; the other class of benefit is instrumental in nature —*i.e.*, the experience of donation is valued, not in itself, but because of the good which it brings about, often in the form of improved relationships between the donor and his recipient/family.

Five of the nine studies report that out of a total of 691 adolescent and adult donors, 635 (92%) felt that donating a kidney to a family member was a positive experience and one which was very worthwhile.[80] In a cohort of 149 donors in 3 studies, 111 (74%) agreed with the statement that their donation experience had been one of the most meaningful experiences of their lives and one which gave them a new outlook on life.[81] One such donor, an adolescent, stated that: "I think I see myself as a little more human and patient...Just the fact of giving part of my body —being cut up and donating to someone who's going to live because of it...I guess I consider it one of the more worthwhile experiences of my life."[82]

Fellner and Marshall noted the changes in the attitudes or the self-perception of their adolescent and adult donors in the following testimony from their donors:

> I feel like I am a better person... The whole of my life is different, I've done something with my life... I feel better, kind of noble, I am changed... For realizing how far I could go for others, I am up a notch in life... I have done a lot of growing up as a result of this, I am much

> more responsible, have grown up... *I think more highly of myself, more sure of myself... I feel a better person for having done it, now I can do anything.*[83]

Similarly, in the 3 studies[84] that examined this issue quantitatively, it was found that 144 of the 253 donors (57%) had increased self-esteem as a result of their donation experience. In addition to this, Westlie *et al*[85] noted that in an examination of 19 aspects of donor quality of life, the cohort of 494 donors were found to have a higher quality of life than that of the general population, while 60% of Simmons, Klein and Simmons' cohort of 111 donors agreed with the proposition that they were "very happy" at 1 year post-transplant, as opposed to 37% of the regional controls and 30% of the national controls who were asked the same questions.[86]

Turning our attention to that second class of benefit mentioned above — the instrumental benefits of organ donation — Smith *et al*, found that in their 536 person cohort, 303 donors claimed that they had always (*i.e.*, pre-donation) had a close relationship with their family member/recipient; in the remaining 233 person subset —those who claimed *not* to be very close to the recipient pre-donation— 224 of these donors (96%) claimed that their relationship with the recipient had improved as a result of the donation.[87] Thus, it is much as Simmons, Klein and Simmons observed:

> The donor and recipient share intimately the experience of a major life crisis, and *they most often emerge with intensely forged ties of closeness* and with a long-term exhilaration and life-appreciation greater than that seen in the ordinary population...Elation at the restored good health of the recipient is frequent.[88]

It seems, then, that intra-family donation can confer significant benefit upon the donor; both in terms of the donors' self-perceptions (increased self-esteem) and in terms of the instrumental benefits that accrue to the donor and her family by way of making the family closer than it might otherwise have been. This is evidenced, in part, by the only slight differences observed between unsuccessful donors and successful donors; regardless of the recipient's outcome, donors most often feel that the experience of donation was in-itself a worthwhile one. The most obvious class of benefit that one might say accrues to the donor is, of course, the pleasure of having saved the life of a loved one, and having the pleasure of being able to continue their relationship with their loved one.

§2.4.3 Discussion. According to the analysis presented above, then, elective uninephrectomy for the purposes of transplantation in healthy subjects is accompanied by a very low risk of mortality (0.03%), a low peri- and post-operative risk of morbidity (30% to 40% — the majority of which are minor and transient), a very low risk of psychosocial problems (6.6%), and a panoply of psychological benefits as a result of the donation experience. These results, taken together with the knowledge that the benefits that accrue to the recipient of the kidney are so great, could lead one to conclude that the risks to the donor are sufficiently low so as to make the use of living related kidney donors a therapeutic modality worthy (on the basis of medical facts) of serious ethical inquiry. This conclusion is not an unreasonable one, but we must nonetheless temper our enthusiasms in order to avoid any premature conclusions; this for the following reason.

One of the most vexing problems in scientific inference generally, and in epidemiologic research particularly, involves the issue of *comparability*: to what extent, the scientist must always keep in mind, are the two populations under study comparable, or similar in the relevant way, to each other? As populations under study become less comparable to each other, so too does the generalizability of conclusions from one population to the next become more tenuous and scientifically invalid.

The reader will surely have noticed that in **§2.4.1.1**, **§2.4.1.2**, and **§2.4.1.3** above, the populations of renal donors in the studies under review were older (patients were, on average, in their late-30*s*) than the populations of renal donors that will be the focus of this essay (generally, ≤ age of consent ≈ 18 years-old). The question which presents itself at this point is, how can we be sure that the risk estimates derived from older populations of renal donors are generalizable to, or true for, much younger renal donors? The short answer is simply that we cannot be sure; we can, however, navigate our way through this uncertainty and in doing so we will address three problems.

First, with respect to the review of peri- and post-operative complications in donors, one should note that within the populations under study, most of the complications occurred in patients who were in the oldest quartile of the total patient population (roughly, ≥ 50 years-old). This is a particular instance of the widely accepted belief that older patients fare worse (have a higher risk of complication) in invasive surgical procedures than do younger, healthier patients. It is therefore not unreasonable to conjecture that strong, healthy pædiatric patients will suffer fewer complications as a result of renal extraction surgery than will older populations. Given these considerations, it is probable that the 30% to 40% peri- and post-operative morbidity rate found above overestimates the morbidity rate that one might find in pædiatric populations undergoing the same procedure.

A second and more serious problem relates to the length of the follow-up period in the studies that examined hypertension, proteinuria, and renal function in nephrectomized patients. As noted above, the mean follow-up period in these studies was between 5.3 years and 14.6 years. During this period it was found that renal function post-nephrectomy was stable and satisfactory in all 1173 renal donors, thus suggesting that prolonged periods of hyperfiltration in the remnant kidney is not accompanied by impaired renal structure or function. The problem, however, is that pædiatric renal donors will have to live longer with only one kidney (on average) than an adult renal donor — assuming for the moment that long term survival is unaffected by uninephrectomy. The question, then, is whether or not enough years of follow-up have been studied to conclude that a pædiatric renal donor can survive unaffected for 6-7 decades post-nephrectomy. The answer is 'probably not.'

To be sure, the data presented above limits our ability to generalize the conclusions from those adult populations to the population of pædiatric renal donors; we can, however, say the following. It has been suggested, and certain evidence exists to support the proposition, that when faced with a decrease in renal mass, younger patients have an increased capacity for renal hypertrophy than do older patients.[89] In other words, following nephrectomy, the remaining kidney of younger patients (those, that is, who are still developing physically) will increase in mass (and, thereby, in the number of functioning nephrons) to accommodate the persistent hyperfiltration. As such, the prolonged hyperfiltration is far less likely to affect the remnant kidney adversely than has been found in populations of patients nephrectomized in adulthood. Given that none of the adult donors were found to have even moderately compromised renal function, this result is encouraging.[90]

Finally, there are very real doubts that could be raised about whether or not the psychological risks and benefits documented in adult renal donors would occur in younger donors. Here the problem of comparability is most marked, for surely the most significant difference between the pædiatric donor and the adult donor is psychological maturity. This questionable comparability has entailments along three axes. First, as noted above, psychological benefit usually accrues to donors in the form of happiness at having been able to help a loved one, or in the form of increased self-esteem. Presumably, a precondition for such benefits is sufficient psychological maturity to understand, say, the concept of altruism, or to be able to reflect upon one's feelings about oneself. And although some adolescents may possess such cognitive assets, it is arguable that younger children — say, ≤ 7 years-old (the age of assent) — might not.[91] Thus, one might ask to what extent pædiatric renal donors are subject to the psychological benefits observed in adult populations.

Second, the harms that occurred in adults (resentment towards the recipient because the recipient was receiving all of the attention after the transplant operation) might be even more marked in the child who is still developing psychologically. Here, the notion of sibling rivalry is key; for, especially in younger children, there is rivalry for the attention of the parents which can be exacerbated by such post-donation shifts in parental attention from the donor to the recipient. There might, third, be a host of unidentified harms that are specific to pædiatric populations, and that require independent research to identify; the data presented above, thus, is uninstructive in this regard.

Thus, although there is doubt as to whether or not the psychological risks and benefits of donation found in adults are generalizable to children, we can say this much. It has been suggested that pre-donation ambivalence to serving as an organ donor and lack of social support are strong predictors of post-donation psychological morbidity.[92] Given these reliable predictors of poor outcome, pre-donation psychiatric screening of donors has been advised.[93] In this way, physicians may be able to determine if a particular prospective child donor is at risk for developing psychological problems post-donation. As Burley and Stiller have claimed: "Contraindications for donation would be evidence of extreme ambivalence, blackmail, coercion, pathological donor-recipient relationships and, in the case of spouses or common-law partners, presence of severely dysfunctional relationships."[94]

§2.5 Conclusions

A few concluding points are worthy of mention. First, the tasks of risk identification and estimation in which we have been engaged is an inexact process, despite the fact that reasonable estimates of the parameters of interest can be determined from a systematic review of the literature. The issue of risk assessment can be even more uncertain; the problem here is one of comparison: the individual engaged in risk assessment must weigh probabilities and magnitudes of *one* group of risks and benefits against probabilities and magnitudes of *another* group of risks and benefits.[95] *A priori*, no one metric exists in reference to which all of the identified risks and benefits may be related for facility of comparison: how, then, is one to determine whether or not a 50% chance that one will receive great psychological benefit outweighs a 1% risk of mortality and a 10% risk of minor morbidity?

Obviously, no one can do this as if following the steps of a carefully planned algorithm. Parents make everyday choices that carry risk for their children all of the time. Parents deciding whether or not they will permit their 10 year-old son to play in the local hockey league, or whether or not they will demand that their 10 year-old daughter wear a helmet when riding her bicycle, surely do not do a comprehensive review of the medical literature related to the frequency and magnitude of risks encountered in these activities prior to making a decision; and yet, they manage nonetheless to decide what is and what is not an appropriate level of risk for their child.

The broader goal of this chapter has been to identify and estimate the risks associated with bone marrow and kidney donation; unless we know this, the task of risk assessment (determining whether or not the risks are acceptable given the family context) would be far more difficult, if not impossible. Hopefully, to the extent possible, we have provided the necessary first step toward a clearer understanding of the child's role in intrafamilial organ or tissue donation.

Endnotes

1. Throughout this chapter and the remainder of this essay I will use the term 'risk' with a specific *quasi*-quantitative sense in mind. Following D.G. Kleinbaum, L.L. Kupper, and H. Morgenstern's outstanding *Epidemiologic Research: Principles and Quantitative Methods* (New York: Van Nostrand Reinhold, 1982 *at* 3), I will use the term 'risk' to denote "the probability of an individual's developing a given disease or experiencing a health status change over a specified period" —'risk,' in this sense, captures what is often meant by people when they say 'chance' in everyday speech.

Risk, so understood, is estimated by examining samples of patients and ascertaining the incidence of the condition of interest in this study population. Thus, in sections §2.2.1, §2.3.1, §2.3.2, §2.4.1.1, §2.4.1.2 and §2.4.1.3 below, when a quantitative analysis of morbidity and mortality risks due to anæsthesia, and bone marrow or kidney extraction is presented, this method of risk estimation will be used.

2. As quoted in: Nicholson RH. *Medical Research with Children: Ethics, Law, and Practice*. Oxford: Oxford University Press, 1986 *at* 87.

3. For an illuminating discussion of research risk in children see: Freedman B, Fuks A, Weijer C. *In loco parentis*: Minimal risk as an ethical threshold for research upon children. *Hastings Cent Rep* 1993;23(2):13-9 *at* 17-8.

4. Keeney RL. Decisions about life-threatening risks. *N Engl J Med* 1994;331(3):193-6.

5. Nicholson RH. *Op cit.*

6. *Ibid.* The reader should note that I depart from Nicholson on the third part of the risk assessment process, risk evaluation.

7. Holzman RS. Morbidity and mortality in pediatric anesthesia. *Pediatr Clin North Am* 1994;41(1):239-56.

8. Lunn JN, Mushin WW. *Mortality Associated with Anaesthesia.* London: Nuffield Provincial Hospitals Trust, 1982.

9. Buck N, Devlin HB, Lunn JL. *Report on the Confidential Enquiry into Perioperative Deaths.* London: The Kings Fund Publishing House, 1987.

10. Tiret L, Desmonts JM, Hatton F, Vourc'h G. Complications associated with anaesthesia — A prospective survey in France. *Can Anaesth Soc J* 1986;33(3):336-44.

11. Tiret L, Nivoche Y, Hatton F, Desmonts JM, Vourc'h G. Complications related to anaesthesia in infants and children: A prospective survey of 40240 anaesthetics. *Br J Anaesth* 1988;61(3):263-9. Another more recent study that examined morbidity and

mortality in the pædiatric population (Cohen MM, Cameron CB, Duncan PG. Pediatric Anesthesia morbidity and mortality in the perioperative period. *Anesth Analg* 1990; 70(2):160-7) report an intraoperative mortality rate of 1 per 4386 anæsthetics, and a postoperative mortality rate of 1 per 4089 anæsthetics. The problem with this study, however, is that the authors make no attempt to assess the extent to which anæsthetics were causally responsible for the deaths. As such, we have no way of knowing if the death was due to the anæsthetic, due to comorbidities present in the patient, or due to other factors.

12. Holzman RS. *Op cit.* On the clinical presentation and treatment of malignant hyperthermia see: Kaus SJ, Rockoff MA. Malignant hyperthermia. *Pediatr Clin North Am* 1994;41(1):221-37; and Lerman J. Controversies in paediatric anaesthesia. *Can J Anaesth* 1988;35(3):S18-S22.

13. Tiret L, Desmonts JM, *et al. Op cit.*

14. Tiret L, Nivoche Y, *et al. Op cit.* A 'major' complication was defined as any "fatal or life-threatening accident or any incident producing severe sequelae, which occurred during, or within 24h of, anaesthesia."

15. Cohen MM, *et al. Op cit.* A 'major' complication was defined as a complication that was "life-threatening or with potential lasting morbidity," while 'minor' complications were "more in the nature of inconvenience."

16. It should be noted that the complication rate found by Cohen *et al* (*Ibid.*) was higher than that found by Tiret (both studies, *Op cit.*) perhaps because Cohen made no attempt to determine the extent to which the anæsthetic was causally responsible for the morbidity.

17. One final concern related to anæsthetic use is worth mention. As one might expect, hospitalization for the younger child can be a frightening experience. It has been suggested that children might become very anxious during anæsthetic induction (by mask or needle), and that the quality of the induction is usually mirrored during arousal from anæsthetic. Thus, if the child is frightened during induction, he may arouse frightened; such an experience has been known to cause long-term psychological sequelae in some. This underscores the need for close parental involvement during induction, and for physician-donor contact before the child enters the hospital for the donation. On this see: Zuckerberg AL. Perioperative approach to children. *Pediatr Clin North Am* 1994;41(1):15-29.

18. More specifically, the diseases that are treated by bone marrow transplantation can be divided into two broad categories: non-malignant diseases, and malignant diseases. Among the non-malignant diseases treated by bone marrow transplantation are: aplastic anæmia, thalassemia, sickle cell anæmia, severe combined immunodeficiency, Wiskott-

Aldrich syndrome, Chédiak-Higashi syndrome, as well as certain genetic disorders; while the malignant diseases treated by bone marrow transplantation include: acute myeloid leukæmia (AML), myelodysplastic syndrome, acute lymphoblastic leukæmia (ALL), chronic myelogenous leukæmia (CML), chronic lymphocystic leukæmia (CLL), multiple myeloma (MM), non-Hodgkins and Hodgkins lymphomas, and more rarely, breast and testicular cancers.

The reader is referred to the most recent textbook dealing with the clinical landscape of bone marrow transplantation: Forman SJ, Blume KG, Thomas ED, (eds). *Bone Marrow Transplantation.* Boston: Blackwell Scientific Publications, 1994. For a thorough, but brief, review of bone marrow transplantation see: Armitage JO. Medical Progress: Bone marrow transplantation. *N Engl J Med* 1994;330(12):827-38. Of interest as well is: Pui C-H. Medical Progress: Childhood leukemias. *N Engl J Med* 1995;332(24):1618-30.

19. Begovich AB, Erlich HA. HLA typing for bone marrow transplantation. *J A M A* 1995; 273(7):586-91 *at* 586.

20. *Ibid.*

21. Bone marrow transplanted from an identical twin is referred to as *syngeneic* marrow or, a *syngeneic* transplant, while bone marrow from another individual is referred to as *allogeneic* marrow, or, an *allogeneic* transplant. A third class of transplant, where the patient donates his own marrow to himself — an *autologous* transplant — will not be at issue in this essay, and is mentioned only for the sake of completeness.

22. This discussion of transplantation immunology borrows from: Begovich AB, Erlich HA. *Op cit.*, and from: Martin P. Overview of marrow transplantation immunology. In: Forman SJ, Blume KG, Thomas ED, (eds). *Op cit.*, *at* 16-21.

23. Recently, however, the clinical importance of mismatches of the so-called *minor* histocompatibility complex gene products *vis-à-vis* the incidence of graft-versus-host disease (GVHD; on this see: *infra*, chapter 3, note 68) in bone marrow transplant recipients has been shown: Goulmy E, Schipper R, Pool J, *et al.* Mismatches of minor histocompatibility antigens between HLA-identical donors and recipients and the development of graft-versus-host disease after bone marrow transplantation. *N Engl J Med* 1996;334(5):281-285; and Behar E, Chao NJ, Hiraki DD, *et al.* Polymorphism of adhesion molecule CD31 and its role in acute graft-versus-host disease. *N Engl J Med* 1996;334(5):286-291.

24. Beatty PG, Anasetti C, Hansen JA, Longton GM, Sanders JE, Martin PJ, Mickelson EM, Choo SY, Petersdorf EW, Pepe MS, *et al.* Marrow transplantation from unrelated donors for treatment of hæmatologic malignancies: Effect of

mismatching for one HLA locus. *Blood* 1993;81(1):249-53; Martin P. *Op cit.*; and Begovich AB, Erlich HA. *Op cit.*

25. Buckner CD, Petersen FB, Bolonesi BA. Bone marrow donors. In: Forman SJ, Blume KG Thomas ED, (eds). *Op cit.*, 259-69 *at* 261.

26. *Ibid.*

27. Jones R, Burnett AK. How to harvest bone marrow for transplantation. *J Clin Pathol* 1992;45(12):1053-7.

28. Filshie J, Pollock AN, Hughes RG, Omar YA. The anaesthetic management of bone marrow harvest for transplantation. *Anaesthesia* 1984;39(5):480-4.

29. Bortin MM, Buckner CD. Major complications of marrow harvesting for transplantation. *Exp Hematol* 1983;11(10):916-21; Buckner CD, Clift RA, Sanders JE, Stewart P, Bensinger WI, Doney KC, Sullivan KM, Witherspoon RP, Deeg HJ, Appelbaum FR, Storb R, Thomas ED. Marrow harvesting from normal donors. *Blood* 1984;64(3):630-4; Petersen FB, Buckner CD, Bolonesi B, Sanders JE, Storb R, Thomas ED, Hansen J. Marrow harvesting from normal donors. *Exp Hematol* 1990;18(6):A676; and Buckner CD, Petersen FB, Bolonesi BA. *Op cit.*

30. Martin P. *Op cit.*, *at* 18. As Martin observes, however, with HLA-identical donors the risk of graft failure is approximately 2%, while the risk of graft rejection is less than 1%.

31. Futterman AD, Wellisch DK. Psychodynamic themes of bone marrow transplantation. *Hematol Oncol Clin North Am* 1990;4(3):699-709 *at* 705.

32. Urban C, Weber G, Slavc I, Kerbl R. Anesthetic management of marrow harvesting from a 7-week-old premature baby. *Bone Marrow Transplant* 1990;6(6):443-4.

33. Sanders JE, Buckner CD, Bensinger WI, Levy W, Chard R, Thomas ED. Experience with marrow harvesting from donors less than two years of age. *Bone Marrow Transplant* 1987;2(1):45-50.

34. Moore FD. *Transplant: The Give and Take of Tissue Transplantation.* New York: Simon and Shuster, 1972 *at* 112. For another excellent discussion of the early years of hæmodialysis and kidney transplantation see: Katz J, Capron AM. *Catastrophic Diseases: Who Decides What? A Psychological and Legal Analysis of the Problems Posed by Hemodialysis and Organ Transplantation.* New York: Russell Sage Foundation, 1975 *at* 35-54.

35. Merrill JP, Murray JE, Harrison JH, Guild WR. Successful homotransplantation of the human kidney between identical twins. *J A M A* 1956;160(4):277-82.

36. *Ibid.*

37. This is also true for extra-renal transplantation (heart, lung, liver and pancreas). See: Starzl TE. The landmark identical twin case. *J A M A* 1984;251(19):2572-3; Fox RC, Swazey JP. *The Courage to Fail: A Social View of Organ Transplant and Dialysis*. Second edition, revised. Chicago: University of Chicago Press, 1978; and Fox RC, Swazey JP. *Spare Parts: Organ Replacement in American Society*. New York: Oxford University Press, 1992.

38. In practice, then, there is a shortage of both 'live' kidneys and cadaveric kidneys, and there is a better prognosis associated with the use of 'live' kidneys. However, in industrialized Western nations — unlike in Japan where since 1964 over 73% of the renal allografts have been derived from living donors (Teraoka S, Toma H, Nihei H, Ota K, Babazono T, Ishikawa I, Shinoda A, Maeda K, Koshikawa S, Takahashi T, Sonoda T. Current status of renal replacement therapy in Japan. *Am J Kidney Dis* 1995;25(1):151-64) — live donor nephrectomy for the purpose of transplantation remains a rare event. In the United States, for example, data from the United States Renal Data System (USRDS) indicates that (on average) 25% of the renal transplant operations performed in the U.S. between 1981 and 1990 have used living kidney donors (Agodoa LY, Eggers PW. Renal replacement therapy in the United States: Data from the United States Renal Data System. *Am J Kidney Dis* 1995;25(1):119-33). Similarly in Canada, according to the Canadian Organ Replacement Register (CORR), just over 15% of all kidney transplant operations performed between 1981 and 1992 used kidneys harvested from live donors (Fenton S, Desmeules M, Copleston P, Arbus G, Froment D, Jeffery J, Kjellstrand C. Renal replacement therapy in Canada: A report from the Canadian Organ Replacement Register. *Am J Kidney Dis* 1995;25(1):134-50), a figure slightly higher than the roughly 11% of Australia and slightly lower than the approximately 16% in New Zealand, both recorded between 1982 and 1992 (Disney APS, for the Australia and New Zealand Dialysis and Transplant Registry. Demography and survival of patients receiving treatment for chronic renal failure in Australia and New Zealand: Report from the Australian and New Zealand Dialysis and Transplant Registry. *Am J Kidney Dis* 1995;25(1):165-75).

Interestingly, however, we see an upward shift in the use of living-related donors when the recipients are pædiatric patients. Data collected from 73 pædiatric renal transplantation centres in the U.S. between 1987 and 1990 indicate that in 1667 renal allograft operations carried out on 1550 children (age ≤ 17 years) 43% of the kidneys came from living related donors (McEnery PT, Stablein DM, Arbus G, Tejani A. Renal transplantation in children: A report of the North American Pediatric Renal Transplant Cooperative Study. *N Engl J Med* 1992;326(26):1727-32) — a figure higher than those cited above (excluding Japan), and higher than that recorded by the European Dialysis and Transplant Association between 1983 and 1986, where 20.5% of 1105 renal transplants in children were performed with kidneys obtained from living related donors (Broyer M. Kidney transplantation in children — Data from the EDTA Registry. *Transplant Proc* 1989;21(1 Pt 2):1985-8).

39. McDonald JC. Discussion of "Dunn JF, Richie RE, MacDonell RC, Nylander WA, Johnson HK, Sawyers JL. Living related kidney donors: A 14-year experience. *Ann Surg* 1986;203(6):637-42," *Ann Surg* 1986;203(6):643. The author's claim that the risks to the kidney donor are "minimal" is clearly an underestimation.

40. Bergan JJ. Current risks to the kidney transplant donor. *Transplant Proc* 1973;5(2):1131-4.

41. Weinstein SH, Navarre RJ, Loening SA, Corry RJ. Experience with live donor nephrectomy. *J Urol* 1980;124(3):321-3.

42. Ogden DA. Consequences of renal donation in man. *Am J Kidney Dis* 1983;2(5):501-11.

43. Bay WH, Hebert LA. The living donor in kidney transplantation. *Ann Intern Med* 1987;106(5):719-27; and Rosenthal JT, Danovitch GM. Live related and cadaveric kidney donation. In: Danovitch GM, (ed). *Handbook of Kidney Transplantation.* Boston: Little, Brown and Company, 1992 *at* 105-18.

44. The weighted average is calculated by dividing the sum of the products of the mortality rate and the number of donors by the sum of the number of donors. The reader should note that, given the 'approximate' nature of the data, this estimate is itself very 'approximate'; moreover, this estimate is not the result of a formal meta-analysis. Although certainly important issues, no attention is paid to determining the comparability of the different populations under study, nor to the presence or absence of trends over time. To do so would take us beyond the scope of the essay.

45. Najarian JS, Chavers BM, McHugh LE, Matas AJ. 20 years or more of follow-up of living kidney donors. *Lancet* 1992;340:807-10.

46. Smith RB, Walton K, Lewis EL, Perdue GD, Herndon G. Operative morbidity among 40 living kidney donors. *J Surg Res* 1972;12(3):199-203; Ringdén O, Friman L, Lundgren G, Magnusson G. Living related kidney donors: Complications and long-term renal function. *Transplant* 1978;25(4):221-3; Weinstein *et al. Op cit.*; Eklund B, Ahonen J, Lindfors O, Kulbäck B. The living donor in renal transplantation. *Transplant Proc* 1982;14(1):68-9; and Yadav RVS, Kumar P, Indudhara R, Minz M, Verma VK. Postnephrectomy evaluation of living related donors. *Transplant Proc* 1988;20(5):799.

47. Weiland D, Sutherland DER, Chavers B, Simmons RL, Ascher NL, Najarian JS Information on 628 living-related kidney donors at a single institution, with long-term follow-up in 472 cases. *Transplant Proc* 1984;16(1):5-7; and Dunn JF, Richie RE, MacDonell RC, Nylander WA, Johnson HK, Sawyers JL. Living related kidney donors: A 14-year experience. *Ann Surg* 1986;203(6):637-42.

48. Smith RB, *et al. Op cit.*, (1 patient); Dunn JF, *et al. Ibid.*, (2 patients).

49. Ringdén O, *et al. Op cit.*

50. *Ibid.*

51. *Ibid.*, (1 patient); Eklund B, *et al. Op cit.*, (1 patient). The authors themselves use the term "nervous problems." It is not unreasonable to assume that what they mean is "mental problems," although they do not specify as much.

52. Ringdén O, *et al. Ibid.*, (1 patient); Weiland D, *et al. Op cit.*, (1 patient); and Dunn JF, *et al. Op cit.*, (3 patients).

53. Weiland D, *et al. Ibid.*, (2 patients); and Dunn JF, *et al. Ibid.*, (1 patient).

54. Weiland D, *et al. Ibid.*

55. Dunn JF, *et al. Op cit.*

56. Fotino S. The solitary kidney: A model of chronic hyperfiltration in humans. *Am J Kidney Dis* 1989;13(2):88-98; and Neuringer JR, Brenner BM. Hemodynamic theory of progressive renal disease: A 10-year update in brief review. *Am J Kidney Dis* 1993;22(1): 98-104.

57. See especially: Hostetter TH, Olson JL, Rennke HG, Venkatachalam MA, Brenner BM. Hyperfiltration in remnant nephrons: A potentially adverse response to renal ablation. *Am J Physiol* 1981;241(1):F85-F93; Brenner BM, Meyer TW, Hostetter TH. Dietary protein intake and the progressive nature of kidney disease: The role of hemodynamically mediated glomerular injury in the pathogenesis of progressive glomerular sclerosis in aging, renal ablation, and intrinsic kidney disease. *N Engl J Med* 1982;307(11):652-9; Brenner BM. Hemodynamically mediated glomerular injury and the progressive nature of kidney disease. *Kidney Int* 1983;23(4):647-55; and Brenner BM, Garcia DL, Anderson S. Glomeruli and blood pressure: Less of one, more the other? *Am J Hypertension* 1988;1(4 Pt 1):335-347.

58. Ringdén O, *et al. Op cit.*; Weiland D, *et al. Op cit.*; Mathillas Ö, Attman P-O, Aurell M, Blohmé, Brynger H, Granérus G, Westberg G. Proteinuria and renal function in kidney transplant donors 10-18 years after donor uninephrectomy. *Upsala*

J Med Sci 1985;90(1):37-42; Bertolatus JA. Friedlander MA, Scheidt C, Hunsicker LG. Urinary albumin excretion after donor nephrectomy. *Am J Kidney Dis* 1985;5(3):165-9; Anderson CF, Velosa JA, Frohnert PP, Torres VE, Offord KP, Vogel JP, Donadio JV, Wilson DM. The risks of unilateral nephrectomy: Status of kidney donors 10 to 20 years postoperatively. *Mayo Clin Proc* 1985;60(6):367-74; Williams SL, Oler J, Jorkasky DK. Long-term renal function in kidney donors: A comparison of donors and their siblings. *Ann Intern Med* 1986;105(1):1-8; Dunn JF, *et al. Op cit.*; Watnick TJ, Jenkins RR, Rackoff P, Baumgarten A, Bia MJ. Microalbuminuria and hypertension in long-term renal donors. *Transplantation* 1988;45(1):59-65; Liounis B, Roy LP, Thompson JF, May J, Ross Sheil AG. The living, related kidney donor: A follow-up study. *Med J Aust* 1988;148(9): 436-44; Najarian JS, *et al. Op cit.*; Liu P-L, Gallery Ed, Grigg R, Mahony JF, Gyory AZ. Renal function in unilateral nephrectomy subjects. *J Urol* 1992;147(2):337-9; and Beekman GM, van Dorp WT, van Es LA, van Bockel JH, van Saase JLCM, van der Woude FJ, Valentijn RM. Analysis of donor selection procedure in 139 living-related kidney donors and follow-up results for donors and recipients. *Nephrol Dial Transplant* 1994;9(2):163-8.

59. Serum creatinine, or its complementary measure, creatinine clearance are indirect methods of measuring renal function based on, respectively, the concentration of creatinine in the systemic circulation (higher levels indicate decreased renal function), and the volume of plasma passing through the kidney required to clear all of the creatinine from the plasma per unit time (lower levels indicate decreased renal function).

60. Although the exact role of increased protein filtration in the development of glomerulosclerosis in humans is unknown and controversial, some commentators have endorsed slight dietary modifications to reduce protein intake post-nephrectomy. See: Bay WH, *et al. Op cit., at* 726.

61. Mathillas Ö, *et al. Op cit.*; Williams SL, *et al. Op cit.*; Watnick TJ, *et al. Op cit.*; and Liu P-L, *et al. Op cit.*

62. It is well documented that hyperfiltration of the kidney is a condition that occurs in females during pregnancy and, as noted above, is believed by some to be a risk factor for systemic hypertension, proteinuria and glomerulosclerosis. However, in a follow-up study of 32 viable births in 23 women who conceived between 2 weeks and 9 years post-donation, 2 cases of proteinuria were detected in women during pregnancy, and were both found to disappear post-partum. A subset of 13 women were followed-up a mean 7.9 years post-nephrectomy (range: 2 to 14 yrs), and it was found that all parameters of clinical interest were normal. On this see: Buszta C, Steinmuller DR, Novick AC, Schreiber MJ, Cunningham R, Popowniak KL, Streem SB, Steinhilber D, Braun WE. Pregnancy after donor nephrectomy. *Transplantation* 1985;40(6):651-4.

63. Aperia A, Broberger O, Wilton P. Renal functional adaptation in the remnant kidney in patients with renal agenesis and in patients nephrectomized in childhood. *Acta Pædiatr Scand* 1978;67(5):611-5; Robitaille P, Mongeau J-G, Lortie L, Sinnassamy P. Long-term follow-up of patients who underwent unilateral nephrectomy in childhood. *Lancet* 1985;1:1297-9; Higashihara E, Horie S, Takeuchi T, Nutahara K, Aso Y. Long-term consequence of nephrectomy. *J Urol* 1990;143(2):239-43; Baudoin P, Provoost AP, Molenaar JC. Renal function up to 50 years after unilateral nephrectomy in childhood. *Am J Kidney Dis* 1993;21(6):603-11; and Narkun-Burgess DM, Nolan CR, Norman JE, Page WF, Miller PL, Meyer TW. Forty-five year follow-up after nephrectomy. *Kidney Intl* 1993;43(5):1110-5.

However, there is evidence to suggest (Bay WH, *et al. Op cit.*) that pædiatric renal donors and those who suffered from renal agenesis may not be comparable populations. It is possible that the mechanism responsible for the development of unilateral renal agenesis operates bilaterally and that the contralateral kidney may also be damaged from birth, albeit far less so. If this is so, then using the population of patients with unilateral renal agenesis to estimate the 3 parameters of interest for pædiatric renal donors may lead to a systematic overestimation of the risks involved in living one's life with only one kidney, for presumably, pædiatric renal donors will have two healthy kidneys at donation. Further research into the ætiology of renal agenesis is required in order to assess the comparability of these populations.

64. It is of interest to know that life insurance companies do not consider donors to be at any higher risk of morbidity or mortality, and consequently, donors are insurable with no documented increase in rates. On this see: Santiago EA, Simmons RL, Kjellstrand CM, Buselmeier TJ, Najarian JS. Life insurance perspectives for the living kidney donor. *Transplantation* 1972;14(1):131-3; Santiago-Delpin EA. Insurance perspectives for the kidney transplant recipient. *Transplantation* 1973;16(6):680-1; Spital A. Life insurance for kidney donors — An update. *Transplantation* 1988;45(4):819-20; and Spital A. More on life insurance for kidney donors. *Transplantation* 1990;49(3):664.

65. Simmons RG, Anderson CR. Related donors and recipients: Five to nine years post-transplant. *Transplant Proc* 1982;14(1):9-12 *at* 11. See especially: Simmons RG, Klein SD, Simmons RL. *Gift of Life: The Social and Psychological Impact of Organ Transplantation.* New Brunswick: Transaction Books, 1987.

66. Here, and below, I will speak of the risks and benefits of 'kidney donation' as opposed to kidney 'extraction', or 'nephrectomy'. The shift in language from 'nephrectomy' to 'kidney donation' is done on purpose and signals a shift from a consideration of the biological concerns of having a kidney surgically removed, to the social concerns involved in giving part of yourself to a loved one.

67. Kemph JP. Renal failure, artificial kidney and kidney transplant. *Am J Psychiatry* 1966;122(11):1270-4.

68. Fellner CH, Marshall JR. Kidney donors — The myth of informed consent. *Am J Psychiatry* 1970;126(9):1245-51; Bernstein DM, Simmons RG. The adolescent kidney donor: The right to give. *Am J Psychiatry* 1974;131(12):1338-43; Simmons RG, Anderson CR. *Op cit.*; Smith MD, Kappell DF, Province MA, Hong BA, Robson AM, Dutton S, Guzman T, Hoff J, Shelton L, Cameron E, Emerson W, Glass NR, Hopkins J, Peterson C. Living-related kidney donors: A multicenter study of donor education, socioeconomic adjustment, and rehabilitation. *Am J Kidney Dis* 1986;8(4):223-33; Sharma VK, Enoch MD. Psychological sequelae of kidney donation: A 5-10 year follow up study. *Acta Psychiatr Scand* 1987;75(3):264-7; Morris P, St.George B, Waring T, Nanra R. Psychosocial complications in living related kidney donors: An Australian experience. *Transplant Proc* 1987;19(2):2840-44; Simmons RG, Klein SD, Simmons RL. *Op cit.*; and Westlie L, Fauchald P, Talseth T, Jakobsen A, Flatmark A. Quality of life in Norwegian kidney donors. *Nephrol Dial Transplant* 1993;8:1146-50.

69. Bernstein DM, *et al. Op cit.*; Smith MD, *et al. Op cit.*; Morris P, *et al. Op cit.*; and Westlie L, *et al. Op cit.*

70. *Op cit.*

71. *Op cit.*

72. *Op cit.*

73. *Op cit.*

74. *Op cit.*

75. *Op cit.*

76. *Op cit.*

77. *Op cit.*

78. Fox RC, Swazey JP. *The Courage to Fail. Op cit., at* 24. Simmons *et al*, in their *Gift of Life*, discuss the shifts in family dynamics that occur before and after transplantation —on this see further: Kemph JP, Bermann EA, Coppolillo HP. Kidney transplant and shifts in family dynamics. *Am J Psychiatry* 1969;125(11):39-44. The problems that can develop between donor and recipient often center around either the donor feeling that she has not been rewarded sufficiently for her 'gift' to the recipient, or the donor feeling that the recipient is not being 'careful enough' with her new

kidney —a kidney that the donor gave to her, and that the donor has an interest in seeing cared for properly. Fox and Swazey have claimed that "the donor may exhibit a great deal of 'proprietary interest' in the health, work, and private life of the close relative who has received his or her organ, on the emotional grounds that, 'After all, it's my kidney... That's me in there'," (*Spare Parts. Op cit., at* 40).

For the recipient's part, feelings of guilt are very common: they have received a gift which they will be unable to repay, and they feel responsible for having put the donor through the risks of kidney extraction. Building on the anthropologist Marcel Mauss' classic *The Gift: Forms and Functions of Exchange in Archaic Societies*, [Trans., Ian Cunnison. Glencoe, Ill.: Free Press, 1954], Fox and Swazey have pointed out that gifts have "...'emotional' and symbolic as well as 'material' value and meaning. In this sense, [Mauss] said, the gift and the obligations attached to it are 'not inert'. Rather, 'the spirit of the thing given' and received is 'alive and often personified.' It 'pertains to a person' and because it does, it creates a 'sort of spiritual bond' between donor and recipient." And as Fox and Swazey conclude, "These anthropomorphic connotations of the gift have proved to be as characteristic of the modern medical scientific and technological milieux in which the giving and receiving of organs through transplantation takes place as of the settings in 'primitive' and 'archaic' societies that were the contexts of Mauss' study," (*Ibid., at* 32). Thus, based on the work of Mauss, Fox and Swazey have claimed that:

> "...[w]hat recipients believe they owe to donors and the sense of obligation they feel about repaying 'their' donor for what has been given, weigh heavily on them. This psychological and moral burden is especially onerous *because the gift the recipient has received from the donor is so extraordinary that it is inherently unreciprocal*," (*Ibid.*; emphasis added).

This aspect of the gift relation of organ donation has been termed by Fox and Swazey —rather aptly— the "tyranny of the gift," (*Ibid.*).

Thus although the morbidity rate was low in these populations, the whole act of intra-family organ donation will, not surprisingly, transform family dynamics and may thereby cause severe psychological strains on all members of the family.

79. Najarian JS, *et al. Op cit., at* 809.

80. Bernstein DM, *et al. Op cit.*; Simmons RG, Klein SD, Simmons RL. *Op cit.*; Sharma VK, *et al. Op cit.*; Smith MD, *et al. Op cit.*; and Morris P, *et al. Op cit.*

81. Kemph JP. *Op cit.*; Bernstein DM, *et al. Op cit.*; and Simmons RG, Klein SD, Simmons RL. *Op cit.*

82. Bernstein DM, *et al. Ibid., at* 1341.

83. *Op cit., at* 1249; emphasis added.

84. Kemph JP. *Op cit.*; Simmons RG, Anderson CR. *Op cit.*; and Simmons RG, Klein SD, Simmons RL. *Op cit.*

85. *Op cit.*

86. *Gift of Life. Op cit., at* 182.

87. *Op cit.*

88. *Ibid., at* 196-7; emphasis added.

89. Aperia A, Wikstad T, Wilton P. Renal growth and function in patients nephrectomized in childhood. *Acta Pædiatr Scand* 1977;66(2):185-92; Simon J, Zamora I, Mendizabal S, Castel V, Lurbe A. Glomerulotubular balance and functional compensation in nephrectomized children. *Nephron* 1982;31(3):203-8; Chevalier RL. Hemodynamic adaptation to reduced renal mass in early post-natal development. *Pediatr Res* 1983;17(8):620-4; Hostetter TH. The hyperfiltering glomerulus. *Med Clin North Am* 1984;68(2):387-98; Robitaille P, Mongeau J-G, Lortie L, Sinnassamy P. Long-term follow-up of patients who underwent unilateral nephrectomy in childhood. *Lancet* 1985;1:1297-9; and Bohannon LL, Barry JM, Norman DJ, Bennett WM. Renal function 27 years after unilateral nephrectomy for related donor kidney transplantation. *J Urol* 1988;140(4):810-1. 'Hypertrophy' simply means 'increased size'; when renal mass is reduced, as in donor nephrectomy, the contralateral kidney will grow in size — the remnant kidney is usually on the order of 30% to 50% larger than before the decrease in renal mass.

90. The implications of these comments for the issue of hypertension and proteinuria in the renal donor are a matter of conjecture. However, given that the compensatory hypertrophy of the remaining kidney is so marked in the pædiatric population, it is likely that the risk of proteinuria would be far less than in donors nephrectomized in adulthood. Moreover, it should be recalled that it is a matter of some debate in the expert medical community as to whether or not proteinuria is of serious clinical importance at all (See: Williams SL, *et al. Op cit.*; Bay WH, *et al. Op cit.*).

As regards the prevalence of systemic hypertension among renal donors, one should note that there is much evidence to suggest that a reduction in renal mass may play an *enabling*, rather than *causative*, role in the development of systemic hypertension. In other words, a reduction in renal mass of 50% may be a necessary but not sufficient condition for the development of hypertension. On this see: Anderson CF, *et al. Op cit.*; Robitaille P, *et al. Op cit.*; Williams SL, *et al. Op cit.*; Bay WH, *et al. Op cit.*; and Liu P-L, *et al. Op cit.*

91. This point is speculative and is not based on any empirical literature.

92. *Gift of Life. Op cit., at* 154-8; Simmons RG, Anderson CR. *Op cit.*; and Morris P, *et al. Op cit.*

93. Burley J *et al. Op cit.*; and Russell S, Jacob RG. Living-related organ donation: The donor's dilemma. *Patient Educ Counseling* 1993:93;21(1-2):89-99.

94. Burley J *et al., Ibid., at* 127.

95. The difficulties can exist even when comparing several studies that examine the prevalence of the same endpoint. For example, depending on the study one consults proteinuria is variously defined as ≥ 100 mg, ≥ 300 mg, or ≥ 500 mg of protein excreted in the urine per day, while hypertension is variously defined as Diastolic Blood Pressure (DBP) ≥ 90 mm Hg, DBP ≥ 100 mm Hg, or DBP ≥ 90 mm Hg **and** Systolic BP (SBP) ≥ 130 mm Hg.

Chapter 3

The Common Law Regarding Tissue and Organ Donation by Minors and Incompetent Persons: An Overview

§3.1 Introduction

The Lord descended to examine the legal city that the jurists had built, and finding that the language of the law was one, decided to scatter legal principles all over the earth. Their language so confounded, jurists henceforward could not understand each other within this jurisprudential Babel. Or so it *seems*, if one reviews the case law regarding donations of tissue and organs by minors and incompetent persons. This body of law was initiated in 1957 in a series of declaratory judgements handed down by the Supreme Judicial Court of Massachusetts acting in its equity[1] capacity.[2] Cases involving minor organ and tissue donation have been variously decided on the basis of one, or a combination of, the following considerations: the necessity of the minor's assent, the sufficiency of parental consent, the best interests of the child, the judgement of the child having been 'substituted' for by the parents or the courts, and a judicial review of the parental decision making, among others. The plurality of principles invoked to guide judicial decisionmaking highlights a simple problem found in this body of jurisprudence: within the courts of law there is a seeming confusion regarding how best to conceptualize intrafamily organ donations by minors.

The courts, having been put into the uncomfortable position of being arbiters of family affairs (to an extent, at least), have resorted to a variety of legal arguments, each emphasizing different principles in different degree. Some courts have understood the main issue at stake in minor/incompetent person organ donation to be one of power: do the courts or the parents have the *power* to authorize the removal of an organ, or of tissue, from a legally incompetent person for the purpose of transplantation into the person of another? These courts then look to precedent in search of judicial power and have found such authority in the common law doctrine of 'substituted judgement'; the courts, or the parents, may 'substitute' their judgement for that of the minor/incompetent person regarding whether or not the donation should proceed based on whether or not they think that the minor or incompetent person would donate if she were competent to decide. Having found such judicial authority, the operation and transplantation may proceed without fear of a lawsuit being brought in the future against the transplant physicians on behalf of the donor.[3]

On the other hand, some courts have articulated a broader conception of the legal issue at stake, one which explicitly involves the notion of the child's 'best interests'. Here the courts ask the following question: do the courts or the parents have the power to authorize the removal of an organ, or of tissue, from a legally incompetent person for the purposes of transplantation into the person of another *when* the incompetent person has not consented, *and* when it has not been shown that the donation will be in the medical best interests of the donor? With no valid consent and no showing of benefit to the prospective donor, some courts have failed to find the power to authorize such donations and have refused to permit the donation of an organ or of tissue from legally incompetent persons. On the other hand, some courts *have* authorized the donation by arguing that the proposed donation is in the best interests —broadly conceived to include psychological interests— of the legally incompetent person. "The Law" has not been unified on this issue.

This short sketch by no means exhausts the jurisprudential issues that have been addressed by the courts over the past 35 years, but it does orient us in legal space. The purpose of this chapter, then, is to present the facts, issues, holdings and reasoning of the courts that have dealt with the issue of donation by incompetent persons since the 1950*s*. Accordingly, we will clarify the principles upon which these judgements have rested and show that, *despite* what the courts have claimed to be the primary issues at stake, the courts have *really* been concerned with one issue above all others — namely, the best interests of the child. Once identified as the primary interest in such cases, one can discern different conceptions of a child's 'best interests' and, what is more, one can detect an evolution of the best interests standard from the time it was first articulated in the declaratory judgements of the Supreme Judicial Court of Massachusetts in 1957, to the more recent case that went before the Supreme Court of Illinois in 1990.[4]

American case law will be our principle subject of analysis in this chapter for the following reason. The broader purpose of this chapter is to introduce and analyze the *concepts* that are of importance in decisionmaking about the permissibility of minor/incompetent person donations. In so doing, we will in two senses be providing the necessary background for our ethical analysis in chapter 4. First, once provided with the issues that have been articulated by the courts, we will then move on in the next chapter to assess the importance of these issues in an ethical, rather than legal, analysis of minor organ donation. Second, and perhaps more importantly, 'the analysis of the issues before the courts will highlight deficiencies in the legal framework and will point the way to a more complete ethical framework. Given the broader purposes of the present chapter, then, a detailed examination of, say, provincial statutes will add very little to the discussion since the reasoning behind such statutes are, as it were, suppressed.

The following outline for this chapter is proposed. Before the examination proper of the common law begins, we will answer the legal question, why is organ or tissue donations by incompetent persons a legal problem at all? This will give us a more complete picture of the issues that are looming in the background and will allow us to proceed to the next stage of the analysis with more understanding. This review will cover approximately 35 years of American case law and will focus on six cases. Following this case by case review, in §3.4 an assessment of the salient points that emerged in the review will be undertaken. Here, the aim will be to extract from the legal principles and arguments, the details that will be of use to us in the following chapter.

§3.2 The Legal Problem

Why, then, is organ and tissue donation by minors or incompetent persons a legal problem at all? If the parents have consented and the physicians believe that the procedures are medically indicated and feasible, why do such cases get argued before the courts? The answer is a simple one, and rests ultimately on the notion of *consent*. At common law, there is an accepted requirement that persons must give a valid consent to all medical interventions.[5] This requirement stems from the right to bodily integrity and the right to self-determination which are both believed to be held by humans by virtue *simply* of being human.[6] This fundamental principle was articulated by the former Chief Justice of the Supreme Court of Canada, Bora Laskin: "The underlying principle is the right of a patient to decide what, if anything, should be done with his own body."[7] It has also been given expression by former U.S. Justice Benjamin Cardozo: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body..."[8] Here, the qualifiers "...of adult years and sound mind..." demarcate the class of persons who cannot consent: minors and mentally incompetent persons. Thus, when the patient is a child or a mentally incompetent person, there is a widely held belief that any 'consent' — any expression, that is, of willingness to undergo the procedure — offered by the patient is insufficient, given that incompetent persons generally, and children particularly, cannot make responsible and voluntary decisions regarding their own well-being, and hence, regarding their own medical treatment.[9]

Not surprisingly, however, the legal incompetence of a person has never furnished the health care worker with an absolute reason to deny such a person medical treatment; at common law, rather, parents are the natural guardians of their children and thereby hold the authority to consent to medical treatment on behalf of their children.[10] These common law sources are further enshrined in provincial and state statutes and require that written consent be obtained before any medical procedures are undertaken. Therefore, the *general* legal position is that parents must give their consent to any medical procedures which are to be performed on their children.[11]

But this does not explain the problem before the courts in minor organ and tissue donation cases. If a valid consent is the only requirement needed to undertake a medical intervention in the legally incompetent person, then surely a parental consent on behalf of the incompetent will be sufficient justification to undergo the procedure. Necessary, yes; sufficient, no.[12] There are two crucial differences that distinguish the case of minor organ donation from other medical interventions on minors: first, the overwhelming majority of medical interventions for minors to which parents consent are, in theory at least, expected to benefit the child in question; the removal of an organ, on the other hand, offers no hope of *physical* benefit for the child. Thus, when the authority of parents to make treatment decisions on behalf of their children is grounded, in small part at least, on an epistemic issue[13] — namely, that the parents *know* better than anyone else, or rather that they *decide*, what is and is not in *their* child's best interests — one might wonder whether parents are choosing responsibly when they consent to the removal of a healthy kidney from one of their children.

The second difference, however, is that unlike other medical interventions where only one child is the object of concern for the parents, the prospect of organ donation between siblings means that parents must consider both of their children's interests when making a decision: can the parents of a desperately ill child in need of a kidney, one might reasonably ask, foreground the best interests of their healthy, prospective donor child when deliberating about whether or not to give a consent to the removal of this child's kidney? Given that the medical team is willing to perform the organ removal and transplantation (this being a precondition of putting the question to the parents), and given that most parents would be willing to do "all that it takes" to save the life of their ill child, one is given to pause: are the interests of the prospective donor child being given serious consideration?

These two distinguishing features of minor organ donor transplantation make the issue of consent even more pointed. For if the prospective donor is legally competent, then both of the above mentioned concerns drop off. First, it is consistent with respect for an agent's self-determination that one be allowed to consent to medical procedures that present very poor risk/benefit ratios. In the context of organ transplantation between siblings, there can be few objections to a competent adult person's consent to donate an organ to a sibling, provided that the person has made a responsible and voluntary consent. In short, if adults wish to engage in risky behaviour, then there can be little objection to their doing so (provided, of course, that the behaviour is socially sanctioned, as in the case of organ donation)[14]. Secondly, if the prospective donor is an adult sibling choosing for himself, then the issue of parental conflict of interest obviously disappears.[15]

Thus, the legal problem does not disappear when parents have consented to the removal of their child's kidney, and the courts have rightly recognized that the issue of parental consent underdetermines what is at stake when the removal of a kidney from a minor or incompetent person for the benefit of another is proposed. The task in §§3.3.1-3.3.6 will be to clarify the manner in which the courts have dealt with the above mentioned issues and to present and analyze the reasoning of the courts.

§3.3.1 Unreported Declaratory Judgements: The Massachusetts Cases of 1957

In 1957, the Massachusetts legal system was faced with a unique situation: the hospital planning to perform a kidney transplantation operation between minor siblings sought a decree (in the form of a declaratory judgement) authorizing its physicians to perform the operation without the consent of the legally minor 19 year-old donor and therefore without fear of liability for non-negligently caused injuries.[16] This case, *Masden* v. *Harrison*[17], was the first of three transplantation cases involving minor donors that the Massachusetts courts pronounced upon in 1957; the two other cases, *Huskey* v. *Harrison* and *Foster* v. *Harrison*[18], both involved 14 year-old siblings and were decided on grounds similar to, if not exactly the same as, those in *Masden*. Due to the similarity of the three cases, only the first and most important case, *Masden*, will be examined closely.[19]

The facts of the *Masden* case are as follows. Leon Masden, aged 19 and a legal minor in Massachusetts, was suffering from chronic glomerulonephritis, a progressively destructive inflammation of the glomerulus. Leon's condition was sufficiently serious that a kidney transplantation was urgently needed for his continued survival. Leon's twin brother Leonard was healthy and had consented to undergo the kidney donation procedure for the benefit of his brother; the parents of the twins had also consented to the proposed procedure.

The issue before the court was the following: given that there was no potential for the minor donor to derive physical benefit from the proposed nephrectomy, the question was whether or not the consent of the parents was sufficient to warrant the hospital in proceeding with the operation. The holding in the case was that the hospital and its surgeons could proceed with the donation operation without incurring liability for their non-negligent actions. The basis upon which the court issued its holding, however, is unclear but seems to involve a determination that the donation would be in the best interests of Leonard, the healthy donor.[20]

Justice Counihan, who was the lone justice in the *Masden* case, highlighted the negative psychological impact that the death of the sick brother would have on the healthy prospective donor:

> I am satisfied from the testimony of the psychiatrist that grave emotional impact may be visited upon Leonard [the healthy brother] if the defendants refuse to perform this operation and Leon should die, as apparently he will... Such emotional disturbance could well affect the health and physical 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 Leon.*[21]

Satisfied that the operation would benefit both brothers, healthy and ill, the operation was authorized and successfully carried out. The two other cases with which we are concerned, both involving 14 year-old donors, were decided on similar grounds; thus, the justices in these two cases felt that the 14 year-old prospective donors were of sufficient intelligence and emotional maturity to both understand the consequences of their decisions and to suffer psychological harm in the event that their ill siblings were to die. As justice Cutter put it in the *Foster* case, the consent of the healthy twin to the proposed kidney donation was "...the result of his own decision, free from pressure or coercion, made with admirable courage, generosity, and appreciation of the factors involved."[22] The justices in these three unreported declaratory judgements, although determining that the prospective minor donors issued effective[23] consent, 'grounded'[24] the authorization of the procedures (primarily) on the finding of potential psychological benefit to the prospective donors.[25]

§3.3.2 *Strunk* v. *Strunk* (1969)

Strunk v. *Strunk*[26] is perhaps one of the most famous cases in the medical case law both for its (mis)interpretation of a legal principle borrowed from the English law of lunacy, and for the reasons used to justify its holding. Tommy Strunk, a 28 year-old suffering from chronic glomerulonephritis and being kept alive on frequent hæmodialysis, was in urgent need of a kidney transplantation in order to remain alive. Given the urgency of Tommy's condition and given that both of his parents were not histocompatible, his only hope for survival was his healthy 27 year-old brother, Jerry, who was an institutionalized mentally incompetent person with a mental age of a six year-old. Jerry's mother petitioned the Kentucky courts for authority to proceed with the transplant operation with Jerry serving as the kidney donor. The issue before the court was the following:

> Does a court of equity have the power to permit a kidney to be removed from an incompetent ward of the state upon petition of his committee, who is also his mother, for the purpose of being transplanted into the body of his brother, who is dying of a fatal kidney disease?[27]

The Kentucky court answered this question in the affirmative, and authorized the removal of Jerry's kidney for the purpose of transplantation into Tommy.

In reaching its decision, the Kentucky courts invoked the inherent equity power to deal with incompetents that had existed in the United States since 1844 (by inheritance from the English courts in the case, *Ex parte Whitbread*[28]). The justices in *Strunk* wrote thus:

> The right to act for the incompetent in all cases has become recognized in this country as the doctrine of substituted judgment and is broad enough not only to cover property *but also to cover all matters touching on the well-being of the ward.*[29]

The original idea behind the doctrine of substituted judgement, arising in the English law of lunacy, is that the courts have the power to deal with the estate of the incompetent *in the same manner as the incompetent would if he presently had his faculties.* Two points are important here in highlighting the extent to which the substituted judgement doctrine was misapplied in *Strunk.*

First, the justices in *Whitbread* made an important distinction that was lost on the justices in *Strunk*; namely, the distinction between a *lunatic* —one who has previously had intact mental faculties— and an *idiot* —one who has never had intact mental faculties. Jerry Strunk had been incompetent from birth, an 'idiot' in the language of the English law. As in the later controversial *Saikewicz* case[30], the appeal to substituted judgement was not only a misapplication of law, but also conceptually confused: the task of acting in the same manner as Jerry Strunk would act *if he presently had his faculties*, is similar to the task of acting in the same manner as someone who has never existed. It is to ask the justices to imagine a person (or, to create a fictional person), similar perhaps in appearance and name to Jerry Strunk, and to imbue this fictional being with intentional states that, once known, will guide the judges in deciding what he would choose were he of sound mind. However, because Jerry Strunk had always been incompetent and had therefore always lacked the capacity to make gifts, there could be no prior acts of gift-making from which to draw an inference of probable donative intent, as was the case in *Whitbread.* The task of applying the doctrine of substituted judgement makes sense only against a background of previous competence; the question in *Strunk* was incoherent from its inception.[31]

Secondly, however, the doctrine of substituted judgement was, until *Strunk*, conceived of, and used *only in*, cases involving the *property* of incompetent persons; in *Strunk*, the law was bent to apply to the *body* of an incompetent. The Court of Appeals of Kentucky seemed to have no basis for claiming that the scope of the original doctrine of substituted judgement could be broadened to include "all matters touching the well-being" of the ward, Jerry Strunk. As one commentator put it: "*Whitbread* was about a lunatic and his money. *Strunk* was about an idiot and his body. The situations were not all that similar."[32]

Despite the association of this doctrine with the case of Jerry Strunk, the issue of substituted judgement in the *Strunk* case obscures the real issue. Although much of the written opinion is devoted to an interpretation of the substituted judgement doctrine, the *real* grounds upon which *Strunk* was decided was, as in the unreported declaratory judgements of the 1950*s* in Massachusetts, a finding that the proposed procedure was in the best interests of the incompetent donor.[33] As the concurring justices wrote,

> ...it would not only be beneficial to Tommy but also beneficial to Jerry because Jerry [is] greatly dependent upon Tommy, emotionally and psychologically, and ... *his well-being would be jeopardized more severely by the loss of his brother than by the removal of a kidney.*[34]

In reaching this conclusion, the court relied heavily upon the testimony of a court appointed psychiatrist as well as an *amicus curiae* brief submitted by the Department of Mental Health of Kentucky. Because Tommy was Jerry's primary link to the rest of the family, and because Tommy was the only one who could understand Jerry's 'defective' speech, it was felt that Tommy's continued survival was essential to Jerry's overall well-being. It was precisely on this psychiatric testimony, however, that the three dissenting justices focused claiming that it was "common knowledge beyond dispute that the loss of a close relative or a friend to a six year-old child is not of major impact," and further that opinions about potential psychological trauma were "at best most nebulous."[35] Whatever the status of expert testimony regarding the potential negative impact on an incompetent or child donor, it is clear that the justices in *Strunk* would not have authorized the operation had they not found that the proposed procedure was in Jerry Strunk's best interest.

§3.3.3 *Hart* v. *Brown* (1972)

Hart v. *Brown*[36] is an interesting case for many reasons; notably, because of the tender age of the prospective donor (7 yrs-old), because of the thinness of the reasons used to support the judgement, and because of the judges' misinterpretation of both *Strunk* and the unreported declaratory judgements in Massachusetts. At the time that the action was brought by the parents, the Hart children were seven year-old, identical twins; Kathleen was suffering from hæmolytic uræmic syndrome and her condition eventually worsened to the point that she underwent a bilateral nephrectomy. She was subsequently kept alive by undergoing hæmodialysis treatments twice weekly. Her twin sister, Margaret, had been informed of Kathleen's condition and of the necessity of the operation; insofar as she was capable of understanding, she wanted to donate her kidney "so that her sister may return to her."[37] The case reached the courts because the physicians were unwilling to perform the operation unless the courts declared that the parents of Kathleen and Margaret, or the guardians *ad litem* of the minors, had the right to give their consent to this operation. This was the question before the court.

The Connecticut court held that the parents of the minor children did have a legal right to consent on behalf of their children, and found judicial authority for their position in three sources: (1) in an earlier case, *Bonner* v. *Moran*[38], which held that nontherapeutic operations were legally permitted on minors provided that the parents or other guardians of the minor had given their consent, (2) in the Massachusetts cases of the 1950*s*, and (3) in the substituted judgement doctrine as it was used in *Strunk*. It is worth mentioning that the appeal to *Strunk* and substituted judgement is misguided, given that *Strunk* was decided (principally) as a result of applying the best interest standard to the incompetent donor.

Once the justices in *Hart* determined that they had the judicial authority to let the parents consent for this procedure, they then turned their attention to the facts and based their decision upon, among other things, a review of parental decisionmaking and a determination of whether or not the procedure was in the best interests of the minor donor. Regarding parental decisionmaking, Judge Testo commented:

> ...it would appear that the natural parents would be able to substitute their consent for that of their minor children *after a close, independent and objective investigation of their motivation and reasoning.*[39]

Thus, given that the need for the kidney transplantation was urgent, that Margaret was the (medically) most suitable donor for Kathleen, that the risks and benefits of the procedure were acceptable for both minors[40], and that the parents had given their consent, the courts took it to be their duty to determine whether or not the parents were well-motivated and had reasoned appropriately.[41]

Although the court regarded the review of parental decisionmaking as their duty, they did not use a strict evidentiary standard in determining a showing of appropriate motivation and reasoning. An example of this low evidentiary threshold occurred in the court's review of the parental decisionmaking when the cited evidence was that a clergyman was called as a witness and testified that the decision by the parents of the donee and donor to proceed with the transplant was "morally and ethically sound,"[42] whatever that might mean. The court itself favourably reviewed the decisionmaking of the parents and stated, as evidence, the fact that the parents had come to their decision "only after many hours of agonizing consideration."[43] Given that such thin "evidence" could satisfy a court of law, one might reasonably ask whether or not the court took seriously its duty to see that the interests of the minor were adequately represented by the guardian *ad litem.*

Like the cases before it, Hart was also grounded (in part) on a finding of potential benefit to the donor as a result of her participation in the procedure. A court appointed psychiatrist examined the prospective donor, Margaret, and testified that she had a "strong identification" with her ill sister, Kathleen. The psychiatrist opined further that the donor would be better off in a family that was happy than in a family that was distressed due to the loss of Kathleen, and more directly, that it would be a "very great loss" to the donor if the donee were to die from her illness.[44] Thus, having found that the risks to Margaret attending unilateral nephrectomy were "negligible," and that she would benefit psychologically from the continued survival of her sister (and hence from her participation in the donation), the Connecticut court authorized the donation of Margaret's kidney for transplantation into her sister, citing in conclusion that just as justice was accomplished in *Strunk* and in the Massachusetts cases, so too would justice be served in this case.[45]

§3.3.4 *In re Richardson* (1973)

The *Richardson* case[46] marked a change in the language that the courts' used when deliberating about the legal basis upon which minor/incompetent person organ donation could be authorized. Contrary to both *Strunk* and *Hart*, the justices in *Richardson* rejected outright the doctrine of substituted judgement as the basis of judicial authority to consent to minor/incompetent person donation; a position that was to be followed in subsequent decisions (see *infra*). In so rejecting the substituted judgement doctrine, the Louisiana court put forth the best interests standard as the appropriate basis upon which to authorize minor/incompetent person donations. The *Richardson* court thus effected a returned to the legal language of the pre-*Strunk* decisions,[47] but contrary to the Declaratory Judgements in Massachusetts, the Louisiana court failed to find any indication that the donation of a kidney would be in the prospective donor's best interests.

The facts of the *Richardson* case are as follows: Beverly Richardson, aged 32, was suffering from chronic glomerulonephritis, a progressive inflammation of the kidneys. After HLA-testing was performed on all but one of Beverly's siblings, it was determined that Roy, Beverly's 17 year-old mentally incompetent brother, was the most suitable potential donor. Roy, who had the mental age of a 3 or 4 year-old, could not render a valid consent, but both of Roy's parents had consented to the procedure on his behalf. Much as in previous case law, the Louisiana court had to determine whether or not Roy's parents or the courts could authorize this surgical intrusion of a minor mentally incompetent person; contrary to previous case law, however, it held that neither Roy's parents nor the courts themselves could so authorize such an intrusion.

The *Richardson* case is notable for the hard line it took on applying the best interests standard *vis-à-vis* Roy's proposed nephrectomy, and for its rejection of the substituted judgement doctrine as articulated in *Strunk*. Regarding Roy's best interests, the justices reasoned by analogy using provisions in the Louisiana Civil Code (LSA-C.C., Arts. 1476, 1477) which prohibited unmarried minors from making any *inter vivos* donations of property, and to a further provision (LSA-C.C., Art. 4275) which "unequivocally" prohibited the donation of the minor's property by his or her tutor, who in this case was Roy's father. The judges concluded thus:

> Since our law affords the unqualified protection against intrusions into a comparatively mere property right, *it is inconceivable to us that it affords less protection to a minor's right to be free in his person from bodily intrusion to the extent of loss of an organ unless such a loss be in the best interest of the minor.*[48]

With the terminal clause, "...unless such loss be in the best interest of the minor," the court laid hold its power to authorize a surgical intrusion into the body of a minor with one proviso: that the bodily intrusion serve the minor's best interests. Having thus explicitly endorsed the primacy of the best interests standard, the court rejected as "highly speculative" and "highly unlikely," the plaintiff's claim that the donation of a kidney would be in Roy's best interests because Beverly, who would remain alive as a result of the transplantation, would be able to care for Roy after the death of his parents.

The other factor that was instrumental in deciding this case was the court's determination that Beverly's need of a kidney transplantation was not urgent, a fact that did obtain in the cases reviewed above. The Louisiana court found, rather, that although a kidney transplant would be "more beneficial" to Beverly, "neither a kidney transplant, nor particularly a transplanted kidney from Roy, is an *absolute immediate* necessity in order to preserve Beverly's life."[49] Moreover, the proposed transplantation was rendered problematic because Beverly had other medical problems, over and above the glomerulonephritis, which might have adversely affected the newly transplanted kidney and thus made the appropriateness of the procedure doubtful on medical grounds.

One justice, although concurring with the majority opinion, disagreed with the reasons proffered by the majority in support of its holding. It was the opinion of this justice that the plaintiffs had failed to show that Beverly's proposed transplantation was urgent, that there were no reasonable alternatives <u>and</u> that the risks to the donor were minimal; having failed to show that these conditions obtained, the question of Roy's best interests was not before the courts at all.[50]

<u>§3.3.5 *Little* v. *Little* (1979)</u>

As in both *Richardson* and *Pescinski* before it, the Texas court in *Little* v. *Little*[51] rejected the substituted judgement doctrine and chose rather to apply the best interests standard. Contrary to these two cases, however, the justices in *Little* did find that the donor's participation in the transplantation would be in her best interests and authorized the donation on these grounds.

An application was filed by the mother and guardian of Anne Little, an otherwise healthy[52] 14 year-old girl who was suffering from Down Syndrome. Anne's younger brother, Stephen, was suffering from end-stage renal disease and although he was being kept alive by frequent hæmodialysis treatments, it was determined that such treatments could not be carried out much longer and that the need for a kidney transplantation was both necessary and urgent. Anne's guardian argued for the donation on the following grounds: (1) Anne was the only suitable donor, (2) the donation would result in "great and tangible" benefits to Anne, (3) the operation would present "no threat" to Anne's life, and (4) "to the best of her ability and comprehension," Anne desired to donate her kidney to help her brother <u>and</u> *would do so if she were competent to make such a decision.* A court appointed guardian *ad* *litem* representing Anne's interests, and assuming an adversarial role, then filed an answer to Anne's guardian opposing the operation on the grounds that there was neither statutory nor constitutional provisions that empowered the court to authorize the removal of Anne's kidney for the benefit of someone other than Anne herself.

The *Little* court began its judgement by rejecting several of the arguments proffered by Anne's guardian as insufficient bases upon which to authorize the donation of Anne's kidney.[53] Once it had dealt with these arguments, however, the Texas court sharpened its focus. The justices stated:

> It is clear in transplant cases that courts, whether they use the term "substituted judgment" or not, will consider the benefits to the donor as a basis for permitting an incompetent to donate an organ...the conclusion of the majority [in *Strunk*] was based on the benefits that the incompetent donor would derive, rather than on the theory that the incompetent would have consented to the transplant if he were competent. *We adopt this approach.*[54]

This comment is important for two reasons. First, as a comment on previous case law, the justices correctly highlight the fact that the doctrine of substituted judgement, despite its prominent place in the written opinions, was really of secondary importance in these decisions. Secondly, the Texas court here explicitly adopts the best interests test as the standard that will guide its decisionmaking, while at the same time it implicitly rejects the doctrine of substituted judgement. Thus, although the Texas court (rightly) chose not to avail itself of the substituted judgement doctrine and could not appeal to any statutes to authorize the donation, it set out to devise a solution based upon the finding that a nephrectomy would be in Anne's best interests.

In reaching its decision the Texas court argued in the first instance that the dangers of the donation to Anne were "minimal," and that, although Anne might be frightened by the foreign surroundings of the hospital, there was nonetheless evidence to suggest that Anne would not suffer psychological harm as a result of her participation. Moreover, the court argued, given (1) the existence of a close relationship between Anne and Stephen, (2) a genuine concern by each child for the welfare of the other, and (3) an awareness by Anne that Stephen was ill and that she was in a position to "ameliorate Stephen's burden," a decision to permit Anne's kidney donation would prevent negative psychological effects (*e.g.*, guilt or sadness) from occurring in the future if Stephen were to die because Anne was not permitted to help him.

The evidence regarding benefit extended beyond the prevention of negative psychological effects and included a finding that positive psychological benefit would accrue to Anne by virtue of her participation. Citing such positive benefits as "heightened self-esteem, enhanced status in the family, *renewed meaning in life*, and other positive feelings," the justices concluded that the facts before them indicated that Anne was "capable of experiencing such an increase in personal welfare from donating her kidney."[55] The Texas court concluded that "there is strong evidence to the effect that [Anne] will receive substantial psychological benefits from such participation," and consequently authorized the donation.[56]

§3.3.6 *Curran* v. *Bosze* (1990)

Heard before the Illinois Supreme Court in 1990, *Curran* v. *Bosze*[57] stands apart from the cases examined above on several grounds. First, the procedure in question in *Curran* was a bone marrow transplantation, a procedure (as noted above in chapter 2) that involves far less risk to the donor than the kidney donations proposed in the previous cases. Second, in contrast to the earlier cases where the proposed transplantation was to occur between siblings, in *Curran* the two potential (twin) donors and the donee were half-siblings, all three of whom shared Tamas Bosze as their father. Third, again unlike the previous cases, there was disagreement between the parents of the prospective donors (3½ year-old twins) about whether or not the twins should go through with the bone marrow donation.[58]

The facts of the case are as follows: Tamas Bosze and Nancy Curran, although never married to each other, parented twins together, Allison and James, who at the time of the proceedings were 3½ years-old. Since their birth, the twins had lived with their mother who was the custodial parent (by virtue of a parentage agreement entered into with Mr.Bosze after they ceased living together and which determined the parentage order). In addition to the twins that he parented with Ms.Curran, Mr.Bosze had three other children with three different women. One of Mr.Bosze's children from a previous relationship, 12 year-old Jean Pierre, was suffering from Acute Undifferentiated Leukæmia (AUL), a rare form of leukæmia which is difficult to treat. Dr.Kwon, Jean Pierre's physician, recommended a bone marrow transplantation for Jean Pierre as the only treatment that could possibly cure him of his disease.

Given that all other potential family members had been tested and rejected as potential donors, Mr.Bosze approached Ms.Curran to ask her to consent to a blood test for the twins in order to determine if they were HLA-compatible with Jean Pierre, and in the event that they were, to serve as bone marrow donors for Jean Pierre. Ms.Curran refused to consent to the blood test. Mr.Bosze then filed an emergency petition in the circuit court and requested that the court find a medical emergency to exist and to order and direct Ms.Curran to "forthwith produce the parties' minor children...for the purpose of compatibility blood testing," and further that if either of the children were compatible that "the Court order and direct that Ms.Curran produce the children...for the purpose of donating bone marrow to their sibling."[59] After the circuit court ruled that it did not have authority to grant the request to compel the HLA-testing of the twins, Mr.Bosze filed a notice of appeal to the Illinois Supreme Court which heard his case.

Mr.Bosze rested his case on an appeal to the substituted judgement doctrine, arguing that the court "should look solely to what the twins would decide to do if they were competent,"[60] and further that the evidence "clearly and convincingly establishe[d] that the twins, if competent, would consent to the bone marrow harvesting procedure."[61] Mr.Bosze's appeal to substituted judgement was strengthened by the fact that the same court had (only one year previously) recognized the substituted judgement standard, and had rejected the best interests standard, as the proper legal basis upon which to decide whether the guardian of a formerly competent, but now incompetent, seriously ill adult patient may exercise a right to refuse artificial nutrition and hydration on behalf of his ward.[62]

The Illinois court (rightly) refused nonetheless to apply the substituted judgement standard and decided that the best interests of the minor donors should guide the court in its decisionmaking. The justices argued that according to *Longeway*, there were two sources of evidence that a guardian could use to guide her decision regarding treatment for the incompetent ward under the substituted judgement standard. The first source of evidence involved a determination of whether the ward had "expressed explicit intent" regarding the proposed medical intervention, while the second source of evidence (absent expressed intent) called for an examination of the ward's "personal value system" in order to determine "likely treatment/nontreatment preferences." Both sources of evidence, the court argued, were unavailable to Mr.Bosze *vis-à-vis* the minor twins.

The court's argument against the applicability of substituted judgement was thus carried out on two fronts. First, if the doctrine of substituted judgement were to be applied to this case, the justices argued, it would mean that Ms.Curran would have to substitute her judgement for that of the twins *based on clear and convincing evidence of the twins' intent.* However, because the twins were only 3½ years-old, they had not yet had "the opportunity to develop 'actual, specific express intent,' or any other form of intent, with regard to serving as a bone marrow donor."[63] Nor was it possible, the court argued in the second instance, to determine 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."[64] Since the twins had not yet developed the "power of self-determination" and were not yet able to make "informed, rational decisions" based upon all of the relevant information, there could be no evidence by which a guardian could be guided in ascertaining whether the twins, if competent, would or would not choose to participate in the bone marrow donation; to do so, the justices wrote, would be to rely on "speculation and conjecture." The court concluded thus:

> Since it is not possible to discover that which does not exist, specifically, whether the 3½ year-old twins would consent to the proposed bone marrow harvesting procedure if they were competent, *the doctrine of substituted judgement is not relevant and may not be applied in this case.*[65]

The court completed its argument regarding the appropriate legal grounds on which this case was to be decided by clarifying that they had rejected the best interests standard in *Longeway* and *Greenspan*, not because they felt that the best interests theory was not viable as law in Illinois, but rather because they had found the doctrine of substituted judgement to be relevant *given the facts* of *Longeway* and *Greenspan*. Whether or not the best interests standard or the doctrine of substituted judgement would be employed in the Illinois courts was therefore a matter to be decided on the facts of the case at hand. Moreover, after a thorough review of the previous case law, the court in *Curran* rightly noted that:

> Notwithstanding the language used by the courts in reaching their determination that a transplant may or may not occur, the standard by which the determination was made was whether the transplant would be in the best interest of the child or incompetent person...We hold that a parent or guardian may give consent on behalf of a minor daughter or son for the child to donate bone marrow to a sibling, *only when to do so would be in the minor's best interest.*[66]

With the adoption of the best interests standard, the burden fell upon Mr.Bosze, as the noncustodial parent, to persuade the court that the withholding of consent by Ms.Curran to the proposed bone marrow harvesting procedure was "clearly contrary to the best interests of the [twins]."[67]

In his attempt to argue that the bone marrow donation would be in (one of) the twins' best interests, Mr.Bosze elicited testimony from many fronts. The physicians who testified all agreed that Jean Pierre's prognosis was poor: figures regarding his chances of survival *if* one of the twins proved to be sufficiently HLA compatible and *if* the marrow grafted well (*i.e.*, the often lethal graft-versus-host disease [GVHD][68] did not set in) ranged from 5% to 50%. Thus even though the twins would most probably be a better histological match to Jean Pierre than either of Jean Pierre's parents, it was a real possibility that Jean Pierre could have died even with the transplant.

Perhaps the most important information elicited from the physicians concerned the risks and benefits that could accrue to the marrow donor. As noted above in chapter 2, the risks attending bone marrow donation are possibly serious (*e.g.*, cardiac arrest due to anæsthesia), but very rarely do they materialize; more often, however, the bone marrow donor can expect pain for about a week at the site of aspiration. The principle concern of the physicians testifying in *Curran* surrounded the issue of the psychological harm that might occur to one of the twins as a result of his or her participation. The potential for child donors to become frightened as a result of their hospitalization was, according to testimony, exacerbated by the fact that Ms.Curran did not support the proposed procedure and that she might not be able to provide the much needed caregiving and emotional support to her child before, during and after the hospitalization. As the child psychiatrist who testified put it: " 'The mother's inability...to concur and to support this process...almost certainly puts the children at very serious risks for having adverse psychological consequences...'."[69]

A further concern of the testifying physicians was that the proposed donation was to occur between half-siblings and that, over and above the biological, histocompatibility problems that this caused, there were social issues raised by such an arrangement. Testimony established that Mr.Bosze had brought Jean Pierre to visit the twins on only two previous occasions, and that each visit had lasted approximately two hours. There was thus absent in the relationship between Jean Pierre and the twins the usual close, filial bond that exists in tradition families; consequently, the typical precondition for the occurrence of psychological benefit did not exist because Jean Pierre and the twins were essentially strangers to each other. The personal testimonies from former donors and parents of child donors, all served to highlight the importance of the family relationship on the donation experience. When asked whether or not they thought that the twins would benefit psychologically ten or twenty years hence from knowing that they had helped, or attempted to help, their half-brother, the physicians opined that it would be unlikely if they did benefit, but that it was virtually impossible to predict whether or not benefit would accrue later in life.

The justices in *Curran*, in reaching their decision to deny Mr.Bosze's motion to compel the HLA-testing of the twins, articulated a three-part theory of the child's best interests based on their review of the testimony. In the first instance, the parent who consents on behalf of the child donor must be "informed of the risks and benefits inherent in the bone marrow harvesting procedure to the child."[70] Second, there must be "emotional support available to the child" from the child's primary caregiver. Given that the child donor would be in the perhaps frightening hospital surroundings, the justices argued that the fear of the child should be minimized, and that the evidence had established that "the presence and emotional support by the child's caretaker [was] important to ease fears associated with such an unfamiliar procedure."[71] Finally, there must be "an existing, close relationship between the donor and recipient" in order for psychological benefit to be a possibility for the donor:

> *Only* where there is an existing relationship between a healthy child and his or her ill sister or brother may psychological benefit to the child from donating bone marrow to a sibling *realistically* be found to exist.[72]

Although the *Curran* court felt that the first element of the tripartite best interests test had been satisfied, they did not believe that the other two elements of the test had been so satisfied. It was the opinion of the court that Ms.Curran's opposition to the procedure was sufficiently strong that compelling the twins to undergo HLA-testing would make it very difficult for her to be supportive for her child during the procedure; moreover, given that Mr.Bosze's involvement in the twins' lives had been to this point limited, the court did not feel that it was realistic for Mr.Bosze to substitute his support for the children for that of Ms.Curran. Finally, the justices believed that there was nothing in the evidence to indicate that Jean Pierre and the twins were known to each other as family; as such, there was no reason to believe that the donor twin would benefit psychologically from helping the half-brother whom he had met only twice before.

In what was an obviously difficult decision to render, the justices concluded that:

> The sympathy felt by this court, the circuit court, and all those who have learned of Jean Pierre's tragic situation cannot, however, obscure the fact that, under the circumstances presented in the case at bar, it neither would be proper under existing law nor in the best interests of the 3½ year-old twins for the twins to participate in the bone marrow harvesting procedure.[73]

On November 19, 1990, a month before the justices in *Curran* released their ruling, Jean Pierre Bosze died at home, a suitable donor having not been found.[74]

§3.4 Assessment

My invocation of the Biblical story of Babel at the beginning of this chapter might now strike the reader as odd. I was careful to point out, however, that in reviewing the case law regarding donations of tissue and organs by minors and incompetent persons, it might *seem* as if one were navigating one's way through a jurisprudential Babel: the *Strunk* court decided that it had the power to authorize the transplant based on what it believed Jerry Strunk would do if he were presently competent, while the *Hart* court decided its case based on the finding that the motivation and reasoning of the parents was 'appropriate'; the *Richardson* and *Pescinski* courts, rejecting the language used in the previous case law, decided that the removal of a kidney *is not* in the best interests of the proposed donor, while the unreported declaratory judgement in Massachusetts and the *Little* court decided that a nephrectomy is in the best interests of the donor; the *Curran* court, although accepting the best interests standard, decided that the previously articulated best interests standards are unacceptable and itself crafted a three-part best interests standard.

But it is slightly more complicated than that; for, it must be granted that the language of the law in these cases has not been unified. Despite the different languages employed (*e.g.*, substituted judgement *vs.* review of parental decisionmaking) and the different meanings of similar terms (*e.g.*, best interests as understood in the *Little* court *vs.* best interests as understood in the *Curran* court) that one encounters in this body of case law, it has been a central claim of this chapter that the conceptual base upon which all of these cases have been decided, or the factor of central importance in all these cases, is the best interests of the donor. Despite these linguistic differences, then, it appears as though the Lord has yet to descend and confound the *thinking* of the courts. Rather, as this chapter has attempted to illustrate, the thinking of the courts in cases involving tissue and organ donations by minors or incompetent persons *is* one, although it is true that the language is multiform.

The courts' reliance on the best interests standard has given rise to some unusual results. Faced with an opportunity to do great good, the courts have attempted to craft a solution to the problem of minor and incompetent person donation and thereby save a life. An uneasy tension arises because the courts are bound to both their traditional role as protectors of society's vulnerable persons, and to their traditional decisionmaking framework in such circumstances, the best interests standard. The problem then becomes the following: how can the courts remain true to their traditional style of reasoning, but at the same time save someone's life? Unfortunately, the courts chose to interpret best interests very broadly and this has resulted in frequently untenable decisions. Recall the justices in *Little* claiming that it would be in the best interests of a 14 y-old girl with Down syndrome to donate her kidney because this would give her "renewed meaning in life." This is undoubtedly a difficult position to support.

Given that the law is united in its implicit or explicit endorsement of the donor's best interests, how will this affect our ethical analysis in the next chapter? A central task of the next chapter will be to challenge the appropriateness of using the best interests standard as the guiding standard when deciding about the permissibility of minor organ and tissue donation. Recognizing what *exactly* is wrong with using the best interests standard in the context of intrafamily donation by minors, both as it is understood by the courts and in general, will point the way to a decisionmaking framework more appropriate to the family context. It is to this task that I will now turn.

Endnotes

1. A court acting in an equity capacity administers justice "...according to fairness as contrasted with the strictly formulated rules of common law. It is based on a system of rules and principles which originated in England as an alternative to the harsh rules of common law and which were based on what was fair in a particular situation." *Black's Law Dictionary*, Sixth Edition. St.Paul: West Publishing Co., 1990 *at* 540.

2. Three cases are widely cited as the first dealing with this issue. *Masden* v. *Harrison*, No.68651 Eq. (Mass., 12 June 1957); *Huskey* v. *Harrison*, No.68666 Eq. (Mass., 30 August 1957); and *Foster* v. *Harrison*, No.68674 Eq. (Mass., 20 November 1957). These were cases brought on behalf of the Boston physicians who were to perform the organ removal and transplant operations. Heard before the Supreme Judicial Court of Massachusetts, the physicians sought judicial approval for removing the kidney from minor children without the consent of the children as a defense to future criminal or civil actions.

3. Fear of civil and criminal liability is what prompted the physicians to bring the cases before the courts in the unreported declaratory judgements in Massachusetts of 1957. There are other reasons why cases such as these make it to court as well, such as parental disagreement over whether or not to subject the child to bone marrow harvesting (*Curran* v. *Bosze*, 556 N.E.2d 1319 (Ill. 1990)), or for example, because parental consent is insufficient and requires the approval of the courts. See, Civil Code of Québec, Article 19: "A minor or a person of full age who is incapable of giving his consent may, with the consent of the person having parental authority, mandatary, tutor or curator <u>and with the authorization of the court</u>, alienate a part of his body only if that part is capable of regeneration and provided that no serious risk to his health results."

4. *Curran* v. *Bosze*, 566 N.E.2d 1319 (Ill. 1990).

5. There are four exceptions to the requirement of consent to treatment: (i) Emergency, (ii) Therapeutic privilege, (iii) Incompetence and (iv) Waiver. On this see, EI Picard. *Legal Liability of Doctors and Hospitals in Canada*. Second edition. Toronto: Carswell Legal Publications, 1984 *at* 41-147.

6. This is also given articulation in the Civil Code of Québec which states: "Every person is inviolable and is entitled to the integrity of his person. Except in cases provided for by law, no one may interfere with his person without his free and enlightened consent," (Article 10).

7. *Hopp* v. *Lepp* (1980), 13 C.C.L.T. 66, 73 (S.C.C.). A similar decision was passed down by the Supreme Court of Canada in the same year. See: *Reibl* v. *Hughes*

(1980), 14 C.C.L.T.1, 12-13 (S.C.C.), in which Chief Justice Laskin also wrote the majority opinion.

8. *Schloendorff* v. *Society of New York Hospitals*, 105 N.E. 92 (N.Y. 1914) *at* 93. Of course, this statement should not be taken to mean that *only* those of adult years and sound mind have interests that should be protected; rather, one of its meanings is that those who are not of adult years and sound mind should have their rights exercised through the person of another who, presumably, has their interests in mind.

9. In stressing that the elements of a valid consent should be that the consent is both 'voluntary' and 'responsible,' I am drawing on the analysis of Benjamin Freedman in his "A moral theory of informed consent." *Hastings Cent Rep* 1975;5(4):32-39.

10. *Hopper* v. *Steeves* (1899), 34 N.B.R.591 (C.A.); *Bonner* v. *Moran*, 126 F.2d 121 (U.S.C.A., D.C. 1941). This position is also articulated in the Civil Code of Québec. Article 14 states: "Consent to care required by the state of health of a minor is given by the person having parental authority or by his tutor."

11. There are exceptions, however. Certain jurisdictions in the U.S. and Canada allow minors to consent to specific kinds of treatment: *H.L.* v. *Matheson*, 450 U.S. 398 (1981), (abortion); *Bellotti* v. *Baird*, 443 U.S. 622 (1979), (abortion); *Planned Parenthood* v. *Danforth*, 428 U.S. 52 (1976), (abortion).

12. Note that parental consent is not necessary for orphans, or when the parents are known abusers of the child. This point was brought to my attention by Benjamin Freedman.

13. I say "in small part" because there are obviously prior considerations that ground parental authority. Thus, for example, if it were the case that the state could "most efficiently/reliably" (whatever these might mean) determine what is in the best interests of all the children within the state, then we would *still* want to allow for parental authority *vis-à-vis* decisionmaking for *their own* children based on the natural relationship and the devotion and love that exists between parent and child. More on this, *infra*, **§4.4.1 The foundations of parental authority**.

14. By "socially sanctioned" I mean simply that kidney donation from healthy persons is viewed as a risky but not unacceptable procedure to submit oneself to. Thus, heart donations from healthy persons, for example, would not be socially sanctioned.

15. There may be conflicts of interest of a different nature in this situation — the adult donor may, for example, feel torn between, on the one hand, helping a loved sibling, and on the other hand, putting himself at risk of death or disability and thereby placing his own family in a vulnerable position should anything happen to him.

16. For good overviews of the cases that will be discussed below, see: Sharpe GS. The minor transplant donor. *Ottawa L Rev* 1975;7:85-105; Robertson JA. Organ donations by incompetents and the substituted judgment doctrine. *Columbia L Rev* 1976;76(1):48-78; Murphy TH. Minor donor consent to transplant surgery: a review of the law. *Marquette L Rev* 1978;62(2):149-69; Bowker WF. Minors and mental incompetents: consent to experimentation, gifts of tissue and sterilization. *McGill L J* 1981;26:951-77; Adams RK. Live organ donors and informed consent: a difficult minuet. *J Legal Med* 1987;8(4):555-86; and Hunter J. Consent for the legally incompetent organ donor: application of a best-interest test. *J Legal Med* 1991;12(4):535-57.

17. *Masden* v. *Harrison*, No.68651 Eq. (Mass., 12 June 1957).

18. *Huskey* v. *Harrison*, No.68666 Eq. (Mass., 30 August 1957); and *Foster* v. *Harrison*, No.68674 Eq. (Mass., 20 November 1957).

19. In reporting on these three cases, I am bound to the commentary of other writers who have had access to these unreported judgements. Any citations of these cases are to the slip opinions as reproduced in either: Baron CH, Botsford M, Cole GF. Live organ and tissue transplants from minor donors in Massachusetts. *Boston U L Rev* 1975;55:159-193, or Curran WJ. A problem of consent: Kidney transplantation in minors. *N Y U L Rev* 1959;34:891-8, as indicated.

20. There is a tension between the two commentators on this issue. Curran claims that the operation was authorized "on the consent of the parent" (Curran WJ. *Ibid., at* 893); this might imply, although Curran himself does not claim, that the *Masden* case stands for the proposition that parental consent in operations such as these is *sufficient* - (it might also imply that parental consent in operations such as these is *necessary*). Baron *et al*, however, explicitly deny this, stating that the Justice in *Masden* wrote in a dictum that an earlier case, *Bonner* v. *Moran* [126 F.2d 121 (D.C. Cir. 1941)], stands for the proposition that parental consent is sufficient, but that the *Masden* case itself does not (Baron *et al. Ibid., at* [illegible]1 note 14). Lack of access to the slip opinions limits my ability to determine this one way or the other, but it seems apparent that the issue of donor benefit, or prevention of donor harm, was key in justice Counihan's reasoning.

21. As quoted in Curran WJ. *Ibid., at* 893; emphasis added.

22. *Foster* v. *Harrison*, No.68674 Eq. (Mass., 20 November 1957); as quoted in Curran WJ. *Ibid., at* 895.

23. 'Effective' as per the *Restatement of Torts* §59 (1939), which held that the consent of a minor would be effective, even in the absence of parental consent, if the minor

was intelligent enough to understand the nature and consequences of the proposed action. On this see: Curran WJ. *Ibid., at* 986.

24. 'Grounded' is perhaps too strong a term; the justices seem not to have articulated any clear legal theory upon which these cases were rested. Rather, they seem to have authorized the procedures after various findings of fact which revolved around the issues of benefit to both recipient and donor, effective consent of the donor, and the consent of the parents.

25. The necessity of finding potential donor benefit continued in later Massachusetts cases. The corollary to this 'rule,' that no finding of potential donor benefit would speak against the permissibility of the operation, was operational in a later Massachusetts case (*Camitta* v. *Fager*, Eq. No. 73-171 [Mass., Sept.5, 1973]), where the mental state of the minor donor (characterized as a combination of mild retardation and schizophrenia) was held to preclude the *possibility* of any psychological benefits accruing to the donor as a result of his participation. On this, see Baron *et al. Op cit, at* 167 note 41.

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

27. *Strunk* v. *Strunk*, 445 S.W.2d 145 *at* 145.

28. *Ex parte Whitbread* (1816), 2 Mer.99; 35 E.R. 878, L.C. The principle of 'substituted judgement' that was coined in *Whitbread* travelled across the Atlantic to the United States and was incorporated into law in New York in *In the matter of Willoughby, a Lunatic*, 11 Paige 257 (NY 1844).

29. *Strunk* v. *Strunk*, 445 S.W.2d 145 *at* 148; emphasis added.

30. *Superintendent of Belchertown* v. *Saikewicz*, 370 N.E.2d 417 (Mass. 1977), a case which also involved a person who had never had intact mental faculties.

31. For a critique of the substituted judgement standard on similar grounds, see: Freedman B. On the rights of the voiceless. *J Med Phil* 1978;3(3):196-210; and Harmon L. Falling off the vine: Legal fictions and the doctrine of substituted judgment. *Yale L J* 1990;100(1):1-71.

32. Harmon L. *Ibid., at* 32. This article is indispensable for an understanding of the legal fiction introduced by the *Whitbread* case, and the impact it had on American jurisprudence, most notably in the following cases: *Strunk* v. *Strunk*, 445 S.W.2d 145; *In re Quinlan*, 355 A.2d 647 (NJ 1976); *Superintendent of Belchertown* v. *Saikewicz*, 370 N.E.2d 417 (Mass. 1977); and *Cruzan* v. *Director, Missouri Department of Health*, 110 S.Ct. 2841 (1990).

One should note, however, that the inappropriateness of the extension of the doctrine of substituted judgment from the *property* of an incompetent to the *body* of an incompetent by the Justices in *Strunk* is not universally agreed upon: "...if property can be invaded because of minimal risk to the incompetent's interests, then presumably the body could also be invaded if the risks are commensurate," (Robertson JA. *Op cit, at* 63).

33. The appeal to substituted judgement was not only unfounded, it was also unnecessary; statutory authority for such a decision already existed under the provisions of Kentucky's declaratory judgment statute: Ky. Rev. Stat. §418.040 (1977). On this see: Murphy TH. *Op cit., at* 155.

34. *Strunk* v. *Strunk*, 445 S.W.2d 145 *at* 146; emphasis added.

35. *Strunk* v. *Strunk*, 445 S.W.2d 145 *at* 150. Evidence exists to the contrary, however: Cain AC, Fast I, Erickson ME. Children's disturbed reactions to the death of a sibling. *Am J Orthopsychiatr* 1964;34(4):741-52.

36. *Hart* v. *Brown*, 289 A.2d 386 (Conn. 1972). For an interesting, but brief, commentary see: Curran WJ. Kidney transplantation in identical twin minors - Justice is done in Connecticut. *N Engl J Med* 1972;287(1):26-7.

37. *Hart* v. *Brown*, 289 A.2d 386 *at* 389.

38. *Bonner* v. *Moran*, 126 F.2d. 121 (D.C. 1941).

39. *Hart* v. *Brown*, 289 A.2d 386 *at* 390; emphasis added.

40. In the words of the court, the risks that unilateral nephrectomy posed to the minor donor were "negligible" (*Hart* v. *Brown*, 289 A.2d 386 *at* 391) — given the results of chapter 2, this is an obvious understatement.

41. I use 'appropriately' for lack of a better term. It is, in fact, unclear why the Connecticut court felt that they should undertake a review of parental motivation and reasoning. One obvious, though unacknowledged, reason would be that the court recognized the potential for the parents to underestimate (in their own minds) the severity of the risk to which they had consented to subject their healthy daughter for the benefit of their ill daughter. Presumably, forcing the parents to articulate their motivations and reasons for the decision might force them to be impartial and to confront the facts of the situation objectively.

42. *Hart* v. *Brown*, 289 A.2d 386 *at* 389.

43. *Hart* v. *Brown*, 289 A.2d 386 *at* 390.

44. *Hart* v. *Brown*, 289 A.2d 386 *at* 389.

45. It is interesting to note that among the list of factors that the judges considered in making their decision was the following: "...there is no known opposition to having the operations performed," (*Hart* v. *Brown*, 289 A.2d 386 *at* 391). One might ask what the guardian *ad litem* for Margaret thought his duty was in this case if the court concluded that there was no known opposition to the operation. Presumably, the duty of a guardian *ad litem* of a minor should be one of advocate and defender of the child's interests. The removal of a healthy kidney is arguably *not* in the best interest of the minor. That a guardian of a minor donor could carry out his duties and still have the court conclude that there was no known opposition to the procedure is indicative of poor representation of the minor. This is not to say that the duty of a guardian *ad litem* is to oppose the proposed intervention all the time; the point here is simply that the nephrectomy was according to the strictly calculated best interest standard used by the courts, arguably grounds for opposition to the procedure. For an extended critique of earlier minor donor transplant cases focusing on the inadequate representation of children's interests, see: Baron *et al. Op cit.*

46. *In re Richardson*, La.App., 284 So.2d 185 (La. 1973).

47. Here again, the point is that the best interests standard has played a central role in the thinking of the courts, regardless of the language they employ. While the *Strunk* court primarily used the language of the substituted judgement standard and the *Richardson* court used the language of the best interests standard, they both were guided by the thinking of the best interests standard. The importance of making the distinction between the language of the courts and the thinking of the courts was suggested to me by Benjamin Freedman.

48. *In re Richardson*, La.App., 284 So.2d 185 *at* 187; emphasis added.

49. *In re Richardson*, La.App., 284 So.2d 185 *at* 187; emphasis added. This notion of a transplant being an "absolute immediate necessity" will be important below (see *infra*, **§4.2 Preconditions for considering the use of the child as donor**).

50. Another case that closely parallels *Richardson* in both facts and reasoning is *In re Guardianship of Pescinski* (226 N.W.2d 180 [Wis. 1975]). In *Pescinski*, the prospective donor was a 39 year-old male with chronic catatonic-schizophrenia who was described by the court physician as "insane seven days a week." As in *Richardson*, the justices in *Pescinski* rejected the substituted judgement doctrine and focused instead on the best interests of the donor; similarly, they found that none of the donor's interests would be served by participating in the donation procedure and disallowed the operation.

51. *Little* v. *Little*, 576 S.W.2d 493 (Tex. 1979).

52. Medical testimony established that Anne suffered from none of the other physical problems that often accompany Down Syndrome such as upper respiratory problems or hypertension. *Little* v. *Little*, 576 S.W.2d 493 *at* 495.

53. The court argued, first, that although the guardian of an incompetent had the right to make medical *treatment* decisions on behalf of the incompetent, nephrectomy was not a medical treatment for Down Syndrome and, as such, the decision to undergo a nephrectomy fell outside of the sphere of parental decisionmaking authority; second, the guardian's appeal to the Mentally Retarded Persons Act (Tex.Rev.Civ.Stat.Ann. Art. 5547-300 [Vernon Supp. 1978-1979]) as legislative recognition of the right of a mental incompetent to participate in organ transplant operations was rejected as untenable.

54. *Little* v. *Little*, 576 S.W.2d 493 *at* 498; emphasis added.

55. *Little* v. *Little*, 576 S.W.2d 493 *at* 499; emphasis added.

56. *Little* v. *Little*, 576 S.W.2d 493 *at* 500.

57. *Curran* v. *Bosze*, 566 N.E.2d 1319. For good overviews of this case, see: Lockemeyer DS. At what cost will the court impose a duty to preserve the life of a child? *Cleveland St L Rev* 1991;39:577-604; Dufault RM. Bone marrow donations by children: rethinking the legal framework in light of *Curran* v. *Bosze*. *Connecticut L Rev* 1991; 24:211-46; Feigenbaum MS. Minors, medical treatment, and interspousal disagreement: should Solomon split the child? *DePaul L Rev* 1992;41:841-84; and Korins JB. *Curran* v. *Bosze*: toward a clear standard for authorizing kidney and bone marrow transplants between minor siblings. *Vermont L Rev* 1992;16:499-539.

58. Apart from these factual differences, however, *Curran* stands above the other lawsuits in that it is the most thoroughly presented opinion, as well as perhaps the most tightly reasoned decision in comparison to the rest. The justices in *Curran* carried out an in-depth review of the previous case law that went far beyond the reviews presented in the other cases, they elicited the expert testimony of 6 physicians [3 pædiatric hæmatologists/oncologists, 1 pædiatric endocrinologist, 1 pædiatric anæsthesiologist, and 1 child psychiatrist], as well as the testimony of three mothers of minor children who had donated marrow to siblings, a brother who had previously donated bone marrow to his sister, and a brother who had received marrow from his brother, in order to better illustrate the personal side of the donation experience.

59. *Curran* v. *Bosze*, 566 N.E.2d 1319 *at* 1321.

60. *Curran* v. *Bosze*, 566 N.E.2d 1319 *at* 1325.

61. *Curran* v. *Bosze*, 566 N.E.2d 1319 *at* 1322.

62. The doctrine of substituted judgement was initially accepted into Illinois law in *In re Estate of Longeway*, 549 N.E.2d 292 (Ill. 1989), and the doctrine was affirmed again a year later in *In re Estate of Greenspan*, 558 N.E.2d 1194 (Ill. 1990).

63. *Curran* v. *Bosze*, 566 N.E.2d 1319 *at* 1326.

64. *Curran* v. *Bosze*, 566 N.E.2d 1319 *at* 1326.

65. *Curran* v. *Bosze*, 566 N.E.2d 1319 *at* 1326; emphasis added.

66. *Curran* v. *Bosze*, 566 N.E.2d 1319 *at* 1331; emphasis added.

67. *Curran* v. *Bosze*, 566 N.E.2d 1319 *at* 1332.

68. GVHD is a disease that affects the bone marrow recipient. When a patient receives an allogeneic bone marrow transplant, he is essentially receiving a new cellular immune system. Preparatory treatment for bone marrow transplantation involves chemotherapy and total body irradiation which is intended to knock out the patient's own marrow (and all of the precursor cells that would eventually make up the person's cellular immune system) such that the new, transplanted marrow can enter the body and replace the old, diseased marrow without coming under attack from the recipient's immune system. Unfortunately, however, the engrafted marrow can itself 'recognize' that it is in a new, 'foreign' body; when this occurs the mature immune cells that originated from the precursor cells of the engrafted marrow can attack, among other things, the skin, the lining of the intestinal tract, and the liver of the recipient. In the already weakened cancer patient, GVHD often results in death.

69. *Curran* v. *Bosze*, 566 N.E.2d 1319 *at* 1335.

70. *Curran* v. *Bosze*, 566 N.E.2d 1319 *at* 1343.

71. *Curran* v. *Bosze*, 566 N.E.2d 1319 *at* 1343.

72. *Curran* v. *Bosze*, 566 N.E.2d 1319 *at* 1344; emphasis added.

73. *Curran* v. *Bosze*, 566 N.E.2d 1319 *at* 1345.

74. Fegelman A. "Boy denied transplant dies in home." *Chicago Tribune*, Nov.20, 1990, *at* C1.

Chapter 4

The Morality of Intimate Relationships and the Child as Donor

§4.1 Introduction

When considering the use of a child as a tissue or organ donor, we are in essence asking whether or not it is permissible to subject a minor child to risks *for the benefit of another* to which she cannot herself consent. Those who are sceptical of the use of a child in this context will focus on two elements; first, that the intervention is non-therapeutic, and second, that the child cannot consent to the procedure herself. That children cannot consent for themselves is not *in itself* problematic; parents are entrusted to make a variety of decisions on their behalf, one of which is medical decisions.[1] But what is suspect about this situation is that the intervention carries (possibly substantial) risk and that the child will receive *no* medical benefits from the procedure.

Usually, as the sceptic would inform us, parents are to be guided in their decisionmaking by what they deem to be in their child's best interests. But what sort of understanding of "best interests" do the parents have if they are considering subjecting their child to the harms of bone marrow or kidney harvesting with no prospect of benefit accruing to the child him or herself? Furthermore, if the parents are not guided by the best interests standard, on what grounds are they justified in agreeing to such an intervention for their child?

If, however, the prospective donor were a competent and otherwise healthy adult member of the family, one could not raise many objections to a decision to donate. Competent adults are allowed to choose to bear as much risk as they want provided that the procedure in question is socially sanctioned. In situations that involve relatively low risk (*e.g.*, bone marrow donation), a common sense presumption is that the adult would surely donate bone marrow in order to save the life of a family member — they are, after all, *family* and family means "doing all that it takes" to help a loved one.

However, the tentative prospective donor herself recognizes that a decision not to donate would be met with both incredulity and hostility, and an awareness of this can take on a coercive spin in the mind of the reluctant donor: after being privately told by the physician that he is a compatible kidney donor for his dialysis-weary and dying daughter, a father decides that he is too afraid to go through with the nephrectomy and asks the physician to lie and tell the family that he is *not* a compatible donor. When the physician refuses to lie, the father feels coerced into donating: "Okay, then. I'll give her my kidney," the father says, "If they knew I could but I wouldn't, it'd wreck the family."[2] As a member of a family, the father has recognized that he may have to accept certain responsibilities, and that failure to do so could lead to a dissolution of the family; one of the glues that keeps the family together, then, is the mutual commitment to one another along with the intimacy that engenders and enhances feelings of love and reciprocity within the family.

The difficulty of refusing to donate observed within the close-knit family is diminished, however, when the prospective donor and recipient are not united within an intimate family unit; and yet, sometimes the moral offense expressed in the face of such a refusal remains. For example, writing the opinion in *McFall* v. *Shimp*[3], a 1978 case involving an attempt to compel an adult to donate bone marrow to his dying cousin, Pennsylvania Common Pleas Court Judge John Flaherty commented: "Morally, this decision rests with the defendant, and, in the view of this court, the refusal of the defendant is morally indefensible."[4] Notwithstanding the moral outrage that is encountered when an adult refuses to help even a distant family member through donation, the legal "solution," namely to compel the donation, is held in similar disdain:

> For a society, which respects the rights of *one* individual, to sink its teeth into the jugular vein or neck of one of its members and suck from it sustenance for *another* member, is revolting to our hard-wrought concepts of jurisprudence. Forceable extraction of living body tissue causes revulsion to the judicial mind. Such would raise the spectre of the swastika and the Inquisition, reminiscent of the horrors this portends.[5]

The purpose of this chapter is to explore some of the above issues as well as others in further detail in the hope of answering the question(s): 'Is it ever morally permissible to use a minor child as a tissue or organ donor for the benefit of another member of his or her family, and if so, on what grounds is it permissible?' First, however, I propose to articulate rough guidelines that might be followed regarding the conditions that should obtain before we can consider the use of children as tissue and organ donors.

§4.2 Preconditions for considering the use of the child as a donor

In what follows, I propose to list and briefly expand upon a few criteria that have found expression in the case law reviewed above in chapter 3 and that should be satisfied before the question before us can be raised. These criteria are meant as rules of thumb and their satisfaction should not be seen as an absolute necessity.

First, the proposed transplantation should be both medically necessary and urgent. In the context of kidney transplantation, for example, this means that a patient with end-stage renal disease need not be considered immediately for transplantation; rather, this patient can, if appropriate, be placed on hæmodialysis until transplantation becomes medically necessary (*e.g.*, the patient is doing very poorly on dialysis) and urgent (*e.g.*, the patient is in imminent danger of dying). It is useful to keep in mind that it is well-established that there are developmental delays associated with long-term dialysis treatment of children; thus, the length of time that the proposed transplantation is *not* necessary and urgent might well be brief.

In the context of bone marrow transplantation, similar considerations apply. If, for example, it is standard practice to treat certain leukæmias with either bone marrow transplantation or chemotherapy, then the availability of the chemotherapeutic treatment modality *may* preclude bone marrow transplantation as the treatment of choice for the patient. Put differently, if chemotherapy and bone marrow transplantation offer similar treatment outcomes for the recipient, then we might claim that bone marrow transplantation is not medically necessary, and thus, that we need not expose a child to the burdens of bone marrow harvesting. If, however, there is a clinically meaningful difference in, say, survival or quality of life between chemotherapy and bone marrow transplantation for a given disease then it will be a matter of clinical and ethical judgement to determine *how much* of an increase in survival (or, quality of life) associated with bone marrow transplantation is acceptable given that this increase in survival is purchased at the cost of exposing a child to the harms associated with bone marrow harvesting. The intention here is not to attempt to answer such questions *a priori*, but rather to stress the importance of situating these ethical deliberations within the context of physician and family.

A further criterion of importance is that the proposed transplantation is felt to be the best treatment available for the recipient, all things considered, and is believed to have a high chance of achieving the clinical outcome of interest. Thus, as was operative in *Curran* v. *Bosze*[6], if the transplantation is the patient's *best* hope of survival *but* the chances of success are still slight, then we might again ask whether or not the small chances of therapeutic success are worth the price paid by exposing a child to the risks of bone marrow or kidney harvesting. We might, for example, feel that the risks of bone marrow harvesting to which we expose a child are sufficiently counterbalanced by, say, a 25% chance of success to the recipient if the child donor is the recipient's last chance; we might, on the other hand, require a significantly higher probability of success if the procedure in question was a kidney transplantation.

If the transplantation is both necessary and urgent and the chances of therapeutic success are felt to be sufficiently high, then the third proposed criterion is that all other possible sources of compatible donors must first be explored prior to considering the child as a potential donor. This proposition has two parts. First, any adult family members of the patient must all have been ruled out as potential donors; if it is possible to have a competent adult serve as a donor and bear the risks of kidney or bone marrow harvesting then this avenue should be explored before we can justifiably expose a child to the risks of tissue or organ donation. Second, the search for live unrelated donors (for both kidney and bone marrow transplantation) and cadaver donors (in the case of kidney transplantation) should have been unsuccessful.[7]

Taken together, these criteria represent reasonable conditions that should be met prior to justifiably considering the minor child to be a tissue or organ donor for a family member in need.[8] The purpose of articulating these rough guidelines is to stress that only as a virtual last resort should uncomprehending children be considered as donors. This is another way to highlight the importance of (the lack of) consent in this case; if adults can be used as donors, then as mature agents who can accept the responsibility of their choices, they should be used before considering the child donor.

At this point we may address the question head on: is it ever morally permissible to use a child as a tissue or organ donor for the benefit of a family member, and if so, on what grounds is it permissible? Some writers have thought that the practice of using child donors is justifiable, given certain qualifications. I would like now, in <u>§4.3</u>, to look closely at previous attempts to answer this question and to then assess these attempts before moving on, in <u>§4.4</u>, to offer an argument concerning what I take to be the most hopeful avenue of inquiry on this question, namely, one which addresses the moral importance of the intimacy (usually) present in families and which attempts to account for this intimacy as it relates to the problem at hand.

§4.3 Potential bases for authorizing the use of the child as a donor

As noted above in chapter 3, the use of a child as a tissue or organ donor is a question that arises in the context of a family. This is so for two main reasons, one biological and one ethical. First, as discussed in chapter 2, given the importance of the HLA gene products for successful transplantation outcomes and given the way in which the HLA genes are inherited, there is a low probability that a child (or an adult for that matter) would be sufficiently histocompatible to be an acceptable donor for an unrelated patient. When the patient is a sibling, however, there is a 1 in 4 chance that the child will be HLA-compatible with her sibling (assuming that both children share the same parents). Thus, purely as a matter of biological probability, the question of children as donors will usually arise only in the context of a family.

There is a second, normative reason that this question is only raised in the context of a family, and it is one that I will for the moment assume is legitimate. I take it that if a prospective child donor and a recipient were strangers to each other, this would raise a reasonable presumptions against the use of the child in this situation. That a child would bear risk for a loved sibling is intuitively plausible given the intimate relation in which donor and recipient stand; that a child would bear risk for an unknown person seems, on the face of it, dubious.[9] This will be examined in further detail below, but for the remainder of this essay the focus will be the child donor within the family.

In what follows, I would like to examine the standard account of decisionmaking on behalf of a minor, the best interest standard, and look at the way in which this theoretical construct has played itself out in actual cases. Accordingly, I briefly revisit some of the issues discussed in chapters 2 and 3, assessing their role in this context.[10]

§4.3.1 Best interests standard. Traditionally, parents have been charged with the duties of caring for their children and have thus been given wide latitude in making decisions for them, provided that their decisions promote the child's best interests. As we have seen, in all of the cases except one (*Curran* v. *Bosze*), both of the parents thought that it was in their healthy, but incompetent, child's best interests to have one of their kidneys removed. It is at this point that the sceptic might reasonably ask: if parents believe that the removal of a healthy kidney is in their child's best interests, then how are we to understand the best interests standard ? In response to the sceptic, I will address two questions: first, how is the best interests standard characterized in theory?, and second, how has the best interests standard played itself out in practice?

A standard account of the theoretical elements of the best interests standard has recently been offered by Allen Buchanan and Dan Brock.[11] The first issue to clarify in this regard is the meaning of the qualifier "best." Recognizing that any given treatment decision will involve many different, possibly competing, interests, Buchanan and Brock argue that:

> ...the best interest principle instructs us to determine the *net* benefit for the patient of each option, assigning

> different weights to the options to reflect the relative importance of the various interests they further or thwart, then subtracting costs or 'disbenefits' from the benefits for each option. The course of action to be followed, then, is the one with the greatest net benefit to the patient.[12]

The parents, then, are instructed to examine the two options, where the child either does or does not donate bone marrow or a kidney, and to imagine the consequences of these options to their child's interests (however these interests are understood). They then select what they think will be the option that will best accord with his interests.

Regarding the nature of the interests at stake, Buchanan and Brock identify two interests that are of importance to us here. First, they identify self-regarding interests, or those that focus on the "current and future interests"[13] of the child him or herself[14]; and second, other-regarding interests, or those that focus on the child's "interest in the good of others."[15] Thus, in the context of intrafamilial tissue and organ donation by minors, self-regarding interests (and, self-regarding costs) include the benefits and risks that are associated with the donation procedure, while the other-regarding interests of the child include the child's present or future interest in the continued well-being of her sick sibling.

How has the best interests standard played itself out in the context of intrafamily donation by minors or incompetents? In a word, curiously. As I argued above in chapter 3, the courts have largely accepted the best interests standard as their guiding decisionmaking principle and they have often argued that the removal of a healthy kidney from a child or incompetent person *does* serve the best interests of the person in question. How have they done this? Briefly, the courts have downplayed the severity of the risks associated with donation, and highlighted the importance of psychological benefit to the donor.

In the first instance, the courts tend to underestimate the risks involved in, for example, kidney donation. As I argued in chapter 2, the risks associated with nephrectomy can be very serious and have, albeit very rarely, included the death of the donor. The rate of complication associated with this procedures tends to be quite low and the severity of the complications tends to be minor (and most frequently materializes in older (age ≥ 50 years) donors). Despite these qualifications, however, it is a mistake to globally characterize such risks as minimal. Undoubtedly impressed by the great good (to the recipient and the family) of authorizing the donation, jurists have wrongly downplayed the harms that can potentially befall the donor.

Consider the following selections drawn from the case law: Arguing that the court should let physicians remove a healthy kidney from a 7 year-old girl, Judge Testo was of the opinion that there were "*negligible risks*" to the donor[16]; in dissent, Justice Day argued that the courts should permit the removal of a kidney from the adult, mentally incompetent brother of a patient because, *inter alia*, "the removal of one of his kidneys would be of *minimal risk to him*"[17]; when faced with a 14 year-old prospective donor suffering from Down Syndrome, Chief Justice Cadena, writing the majority opinion, authorized the donation stating that the "*dangers of the operation are minimal*"[18]; while the Justices in *Strunk* endorsed the donation of a kidney from an adult incompetent based on many reasons, among which was the 'fact' that the nephrectomy could be effected with "*minimal danger*" to the donor.[19] Needless to say, the risks of nephrectomy have been understated; nephrectomy is a serious, and invasive procedure, and although the majority of kidney donations do proceed with only relatively minor and transient complications, there are major peri- and post-operative complications that require further hospitalization of the donor.

An important second component in the reasoning of the courts in all the cases presented above was the idea of psychological harm and benefit. The important point here is that one of the necessary preconditions of receiving psychological benefit is that the donor has sufficient 'mental equipment' to recognize the *social* aspect of donation; that is, the donor must be aware not merely that his or her kidney has been removed, but rather that they have helped their sibling *by donating* in a way that few (perhaps no) others could ever do.[20] The distinction I am attempting to illustrate here is similar to that captured by the shift in language use from "kidney extraction," or "nephrectomy" —purely a biological description— to "kidney donation" —an act that takes place in a social context and which carries specific meanings. Thus, if the donor is so severely mentally incapacitated that he will not only fail to understand why he is in the hospital, but also not understand the important role that he has played in the care of his sibling, he will most likely *not* receive any psychological benefit as a result of his donation.[21]

To return to the task at hand, *exactly* what is meant by psychological best interests is often unclear, but it seems to involve at least the following points, most of which implicitly rely for their force on the assumption that the donation will be a success. First, the donation can have instrumental value to the donor: in donating, the donor has saved the life of a sibling and will therefore have a sibling to grow up with and to share a life with, each of which brings with it certain identifiable social and emotional benefits. Second, *ceteris paribus*, growing up in a household unaffected by the tragic loss of a sibling or child is possibly more conducive to psychological stability and general mental health than growing up in a family that has been struck by such a tragedy. Third, even if the donation is ultimately unsuccessful, the donor may receive some comfort from the recognition that everything possible was done to help her sibling, and that her role in the medical treatment was crucial. Such an appeal to the intrinsic good of donating has been made before in the courts: "The majority opinion would forever condemn the incompetent to be always a receiver, a taker, but never a giver...he is forever excluded from doing the decent thing, the charitable thing."[22]

What are we to make of this? The principal problem with the psychological best interests argument is that it seems to be nothing more than a *post hoc* rationalization in the service of a previously determined conclusion. For consider what is really being asserted when one authorizes the donation of a kidney from a minor on these grounds. *It is in the child's best interests to*: (*i*) be exposed to the unfamiliar and frightening environment of a hospital; (*ii*) be exposed to the risks attending the use of general anæsthetics; (*iii*) be exposed to the potentially serious peri- and post-operative risks associated with the surgical removal of a healthy kidney; (*iv*) be exposed to the potentially serious long-term risks associated with extended hyperperfusion of the remnant kidney, including unknown risks; (*v*) potentially experience the psychological trauma following a failed transplantation attempt; (*vi*) potentially experience the "psychological benefits" following a successful transplantation attempt. As one jurist has written, the appeal to the psychological best interests of the donor as a justification for authorizing the donation is "pretty thin soup on which to base a decision."[23]

What seems apparent in the reasoning of the courts is that when faced with the situation of the life or death of the child recipient, they interpreted their guiding decisionmaking principle —the best interests of the child donor— as broadly as necessary in order to help a sick child. The claim here is not that the "interests" identified by the courts are not *really* interests of any importance; on the contrary, those "psychological interests" are surely important interests to address. Rather, although the psychological interests that the courts identify can arguably fit into a lexicon of self-regarding and other-regarding interests, it is the fact that the courts believed that such psychological benefits *outweighed* the heavy (potential) psychological burdens *as well as* all of the actual and potential physical risks associated with the surgery. Given the decisionmaking procedure and its emphasis on best interests, it is the conclusion of which one is sceptical.

A further and deep problem is that *as* minors, much as with mentally incompetent adults, the prospective donors will probably *not* be able to experience the psychological benefits because of their insufficiently developed mental and emotional capacities. Thus, even if the courts are correct in their identification of psychological benefits, and even if such benefits would materialize in an adult and outweigh the burdens associated with donation, might one not be concerned that the child will not experience this benefit because of her immaturity? Perhaps, but unlike the case of the mentally incompetent person who perhaps will *never* understand what has been done to his body and to his sibling, the young donor will (barring some unforseen tragedy) develop mentally and *come to understand* that she played a key role in her sibling's medical treatment; she may also become a different (perhaps better) person because of the donation experience even if this donation is, as it were, "experienced" only many years later. Thus, the practical possibility that the social aspect of donation *may become* part of an individual donor's life story should be kept in mind when thinking about the issue of minors as tissue or organ donors.

The use of psychological best interests is unusual in this context, but there seems to be something legitimate about giving consideration to non-physical interests in the decisionmaking process. The incongruity one senses when faced with a judgement to the effect that the removal of a healthy kidney is in a minor's best interests, comes, I think, from the misguided attempt to "fit" the psychologically (or emotionally, or morally) important elements of the situation into the narrow best interests calculus of adding and subtracting self-regarding and other-regarding benefits and costs. Insofar as one has "successfully" packed such concerns into a cost/benefit analysis, so too has one hived off what is of importance in such concerns and thus reduced their force by removing them from their appropriate context in all its particularity.

There seems to be something other than "interests" at play here and it is related in important, even crucial, ways to the fact that the prospective donor and recipient are intimately related to each other through common family membership. It is *here, in the family* that the grounds for subjecting a child to the risks of donation *—if they exist at all—* are to be found. As a first and incomplete try, we can get at this factor by recognizing that, although the proposed nephrectomy might not be in the best interests of the child donor considered merely as an individual, it might nonetheless be in the best interests of the family *as a whole* (what this might mean is by no means uncontroversial) that the child bear the burdens of the donation. That jurists have tried to bring this inchoate element to articulation through the best interests standard, speaks to their traditional method of reasoning and, in especially egregious instances, perhaps to their intellectual dishonesty, but not necessarily to the error of their conclusion. The rarefied version of psychological best interests simply will not do the work the jurists try to make it do. We should instead be focusing our attention on the family and the interests or concerns inherent in that context. What, then, is involved in the morality of intimate relationships and the ethics of the family, and do they have a sufficiently strong hold on our allegiances to justify the procedure under consideration?

§4.4 The ethics of the family

I would like to claim that allowing a child to act as a tissue or organ donor for the benefit of a sibling is a decision that can *arguably* fall within the scope of parental decisionmaking authority. To be sure, whatever is argued will necessarily have to be sensitive to important facts, such as, the degree of risk to which we are proposing to subject the child and the age of the child. In what follows, no attempt will be made to offer a fool proof decisionmaking algorithm — life and ethics, fortunately, are messier than that. Rather, I will bring to the fore certain considerations that I feel are crucial to this issue; in a sense, then, I attempt to create a space within which parental decisionmaking can best be situated, namely, within the family itself.

What do we mean by the family? To say the least, the family has taken on a plurality of forms in the contemporary world. Even if we restrict our focus to the Western democracies, we encounter a wide range of groupings of human beings that we could justifiably label as "families": traditional two parent families where one of the parents stays at home with the child(ren) while the other works outside of the home[24]; more modern families where both parents work outside of the home and child-rearing duties are more evenly shared; single parent families; and families of same-sex couples. All of these associations are, as Mary Ann Glendon has written, "discrete group[s] within the horde."[25] We can add to Glendon's comments somewhat. For the purposes of this essay, 'family' will mean:

> ...an intense continuing and intimate organization of at least one adult and child, wherein the child is extensively and profoundly dependent on the adult, in which the adult supplies the child with its emotional and material needs, and in which the parent is dependent on the child for a certain kind of intimacy.[26]

By no means complete, this definition does get at the types of families with which we would be dealing in the context of intrafamilial organ donations. In such families the parents are charged with the duties of providing the necessities of life for their dependent children and have successfully discharged those duties.[27] Families, so characterized, will still cover a broad spectrum, from very intimate families where "family comes first," to more loosely organized families where, although each cares for the well-being of the others, concern for "the family" motivates few actions.

In the next two sections, I look at two main issues: first, the nature of the foundations of parental authority, and second, the scope of parental decisionmaking authority. In so doing, it is hoped that a clearer understanding of how we should think about intrafamilial organ donations by minors will emerge.

§4.4.1 The foundations of parental authority. In order to articulate the proper scope of parental decisionmaking authority, we first need to ask: why do we feel that from among all of the *other* individuals and institutions in society, parents are best placed to rear the children that they themselves bring into the world?[28]

Generally, parents assume the duties of child-rearing because of the natural link between parent and child. I use the term "natural link" in two different, but related senses. First, and most commonly, children are related to their parents genetically by virtue of having been brought into biological existence by them. In such circumstances, the state entrusts the parents with the care of the child because it is reasonable to believe that the parents *will* discharge their duties to provide the "necessities of life" spontaneously, out of love for their dependant child.[29]

Often, however, this genetic link is absent or, tragically, parents are no longer motivated to care for their child as they should —*e.g.*, as in the case of maltreated and abused children— in which case the state may justifiably intervene and transfer the child from the custody of his biological parents to that of more acceptable foster parents. Here, the second sense of the natural link is operative. Even if the parents are not genetically related to the children, adults can still be naturally linked to children through social parenthood. This link between parent and child, also operative in the case of biologically related parent and child, is the primary link in the case of adoptive parents and foster parents who, although not causally responsible for bringing the children into existence, nonetheless assume the parental duties of care. The overarching point here is that the parent child relationship is fundamentally a *moral* or *social* relationship, rather than a biological one.[30]

Moreover, largely as a result of these natural links to their children, parents tend to keep the best interests of their children in mind during decisionmaking and seem to be best placed, as the primary rearers of the children, to provide the skills needed for the tasks of adulthood. I want to make two points here. First, situating authority over children with the parents of the children can be justified on consequentialist grounds, namely, that parents will probably do a better job than any other members of the community or any institution of the state, contrary to Plato's suggestion, in the *Republic* and the *Laws*, that we should dissolve the private family and place all children in public nurseries. The social presumption that parents will be more successful at rearing their *own* children is evidenced by society's general respect for family privacy and autonomy.[31] Although the state performs many important functions in our lives, it is limited, as Joseph Goldstein has noted, in its ability to promote personal relationships but is quite adept at destroying them.[32]

In noting that parents are best placed to provide the skills needed for the tasks of adulthood, I am gesturing at my second point by invoking Rawls' notion of "primary goods."[33] As Rawls notes, primary goods "are things which it is supposed a rational man wants whatever else he wants," by which he means that primary goods are those things that more, rather than less, of will increase the chances that an agent will successfully realize her life plans, whatever they may be. Among the primary *social* goods Rawls includes rights and liberties, opportunities and powers, income and wealth[34], and, most importantly, self-respect [35]; among the primary *natural* goods Rawls includes health, vigour, intelligence and imagination.[36] Thus, because parents are the primary caretakers of their children *and* because they love them, they will probably do a better job than others at giving their children the goods that are widely considered to be important for human flourishing, whatever one's conception of flourishing happens to be. As Goldstein has commented: "As *parens patriae* the state is too crude an instrument to become an adequate substitute for parents."[37]

It is important to note, however, that parental authority is grounded in the intimacy of human relationships. In other words, parental authority is justified by virtue of the personal, intimate relationships that occur, or can occur, within families. Thus, even if parent and child are not biologically related to each other, and even if somehow (exactly how would be difficult to imagine) some institution of the state could raise children in the "best possible way" — roughly, though not uncontroversially, that their interests would be optimized, and they would be furnished with the maximum number of primary goods necessary for adult life — there should *still* be a presumption in favour of the parental authority to raise children because of the intimacy and meaning that life within the family engenders.

What is at stake here, if one accepts the foundational role that intimacy plays in parental authority, is nothing less than the meaning of particular lives: "Perhaps even more valuable than the protecting, nurturing, and socializing functions of families is their central importance to human identity — they play the primary role in making us the people we are."[38] Put differently, we derive the meaning and value in our lives from our intimate associations, the most foundational of which arguably is that of our family. It is within the family that we first learn to be moral agents; it is where we learn about the important things in life: giving and receiving, love, trust, loyalty, forgiveness, responsibility, and justice, to name a few. And part of what is meaningful about being a member of a family is that we can cultivate our intimate relationships with family members in a manner of our *own* choosing. Not only is this a good for parents, who are the ones exercising the decisionmaking authority in accordance with their own conception of the good life, but it is also a good for the children, who will ultimately learn to function as a moral agent in the world. As Hilde and James Nelson have written: "families impart in their children a sense of the reality of other persons that is the foundation of morality... It is our families who take us on a journey from egoism to intimacy to sociality."[39]

§4.4.2 The scope of parental authority. If the above are among the reasons for accepting parental authority, what follows *vis-à-vis* the scope of parental authority? What decisions, in other words, are parents permitted to make on behalf of their children, and does the decision to volunteer one's child to donate an organ fall within the bounds of reasonable parental choice?

It has often been said that family matters are private matters and that others, including the state, should mind their own business and let family matters remain private. While this may be a good policy for the most part, parental decisionmaking authority is not absolute. Although there is good reason to keep certain family matters free from public scrutiny, there are reasons why we should not do so at all times and situations where we can legitimately ask whether or not a decision that materially affects a child falls within the bounds of reasonable parental choice. It can be dangerous for the state to turn a blind eye to the family, especially when one considers the vulnerable members of the family. Too often, unfortunately, state policies of non-intervention in the family have meant that some members of the family are subject to the "unrestrained authority" of an other member, usually the male "head of the household"— various forms of child abuse as well as the former marital exception to rape laws come to mind as especially disturbing examples of this policy of non-intervention.[40] Given these considerations, it seems clear that parental decisions which materially affect children should come under public scrutiny.

To say that the scope of parental authority is not absolute, however, is to say very little; parents are still given wide discretion regarding the decisions they may reasonably make. To be sure, they must keep their child's best interests in mind, but *how* are they to do this? Lets look at two ways (both of which I think are wrong) in which parents can do this before we examine the way they should consider their child's interests.

It is consistent with a regard for one's child's best interests that parents seek to *optimize* their child's interests, however "interests" are understood. Although parents are certainly permitted to do this and might be considered praiseworthy on account of their devotion to their child, optimization of a child's interests —or, making choices in life that secure the *very best* outcomes for the child, all things considered— seems to be too stringent a standard to which parents must be held. Were the optimizing strategy the rule, the parents would have to devote their lives to the optimizing of their child's interests; presumably, leisure time activities for the parents would for the most part be impermissible because such time could always be spent either with the child, or working for the betterment of the child.[41] In addition to undermining the integrity of the parents (and, the family) such a policy of optimization would result in an unequal and perhaps unfair distribution of scarce family resources — as, for example, when the parents would have to forego the purchase of the new car in order to send their child to the *very best* private school in the area, as opposed to the second best, but still outstanding, private school.

If parental authority is neither absolute nor excessively restricted by the optimization of the child's interests, how then should parents be guided in their decisionmaking? As noted throughout this essay, the best interests standard has been the workhorse of those who have sought to justify tissue or organ donations by minors. But as we have also seen, the justification —if we can call it that— of the minor's participation as a donor has occurred by appeal only to the psychological interests of the child. I think we have some reason to be suspicious of whether or not psychological interests as they have been understood are really *interests* at all when invoked in the case of the very young child, but even more generally, if they *are* interests, we have even more reason to doubt whether they are sufficiently robust to justify the burdens of tissue or organ donation.

But there is a criticism of the best interests standard that cuts deeper than this, and it is one that is not dependent for its force on the way interests are understood. The question is whether or not parents should be held captive by this decisionmaking framework: should parents, in other words, only consider the *individual* interest of the donor (it is in his psychological best interests to continue to have a sister) and the *individual* interests of the recipient (it is in her medical best interests to get a highly HLA-matched kidney) when making such a decision? Is the best interests standard the right standard at all? This question may appear absurd —"But *of course* it's the right standard," urges the jurist, incredulous at the mere posing of the question— but I think it is a question that we should seriously consider; even if we do not dispense with best interests entirely, might we not gain a better understanding of the morally relevant aspects that should factor into such decisions if we honestly probe the limitations of the decisionmaking framework that has, until now, dominated discussions of this topic?

If we are to successfully address the scope of parental decisionmaking authority, then we must change our emphasis from the "top-down" approach of focusing on the decisionmaking framework first *and then* applying it to the family context, to the "bottom-up" approach of focusing on the family context first *and then* finding out how best to approach the question of the child as donor. Only then will we be able to meaningfully ask about what decisions can and cannot be made by parents on behalf of their children.

Strict adherence to the best interests of the child is problematic to the extent that it fails to account for what is important in families: the best interests standard is a formal and abstract framework, while families are intimate and particular associations; the best interests standard is impartial, while families are essentially partial and favoritist; the best interests standard is applied to an individual, while families are collectivities.[42] The attempt to cram a formal relation into an intimate context does violence to the morally significant aspects of the family relationship. If we accept that the application of the best interests calculus to the problem can often mischaracterize what is of importance in the family, we would be well-served to adopt a broader approach to this issue.

I think that there are two related ways to broaden the scope here, and in so doing, to paint a truer picture of what we should be doing when we think about the boundaries that should be placed on parental decisionmaking authority. In the first instance, we may recognize that one of the meaningful aspects of parenting is the opportunity that it affords parents to rear their children according to their own conception of the good life; in order for this to happen, families must be accorded a certain degree of privacy —or, freedom from unwanted intervention— such that the intimacy that is foundational to the integrity of the family is allowed to flourish, and the parents are allowed to teach their children the virtues of their choice. This is one of the many functions of the family: "Families serve as our first and perhaps most fundamental school for moral formation," as Hilde and James Nelson have put it.[43] But this will only bring us part of the way toward the conclusion that parents can sometimes sacrifice the strict interests of their children because of their desire to rear a child in one way as opposed to another. In the second place, the degree to which we will accept that they can sacrifice the strict interests of their children broadens significantly if we bring to articulation those interests that are, in a deep sense, *familial.* There are, I would claim, certain "family interests" that run deeper than a parent-orchestrated education in the virtues, and that extend far beyond a best interests calculus that concludes that, all things considered, it would be in the best interests of the family that the healthy child bear an inordinate burden for the benefit of the rest of the family.

In the first place, it is uncontroversial to claim that parents can at times legitimately limit the freedoms of their children at times. One reason for this is that since children are often unable to make responsible choices for themselves, parents are justified in limiting their freedoms in order to promote their well-being. Thus, for example, we would say that the parent who forbids her son to play ball on the shoulder of the highway was entirely justified in so restricting his liberty. Not all interferences with liberty are designed to serve the well-being of the child, however, but parents are nonetheless justified in limiting their freedom in many cases. Thus, as Schoeman notes, such justifiable interferences might include "requiring children to help with family chores, to go on vacations which will surely strike them as boring or inconveniently timed, or limiting the occasions on which they can invite friends over."[44] Interferences of this nature, one might not unreasonably contend, can be justified by blanket appeal to parental authority: the parents are permitted to impose these limits because they are the parents and "what they say goes" (within limits, of course).

As Nelson has commented:

> ...parents intervene in their children's lives on the basis of undemonstrable views that there are things that matter apart from a child's own interest, and this is often precisely what they are trying to convey by means of the intervention.[45]

As this quote arguably intimates, parents can limit the freedom of their child at times because this may be what is required in order for the parents to mold their child's character in the manner that they see fit: "Teaching the virtues doesn't come easy," one can imagine a parent saying. In practice, this means that parents can often make children do things that they might not want to do. The examples given above by Schoeman can all be thought of (minimally, at least) as serving some virtuous end: cooperation and responsibility (chores), sociability and filial piety (vacation), and, perhaps, responsibility (limit on friends).

But parents often impose burdens on children that go further than a mere restriction of liberty. It is not merely that sometimes a child will not want to do something because, say, he finds it boring, but rather that what the child is being forced to do might be *harmful* to the child. We do not usually have a problem when a parent deprives a child of his *wants* —candy, for example— provided that in so doing, the parent is addressing one of the child's *needs* —a nutritious and well-balanced diet. The question here is whether or not some choices that are harmful to the child can nonetheless be permissible *even if* they clearly address the needs of the child. For example, it is reasonable to count among a child's needs that of education, and in particular, the skills of reading and writing. Given a clearly identified and legitimate need such as education, it is certainly true that we would find it unacceptable if a parent were to physically abuse her child —say, by beating him with a cane— merely to bring about the valuable ends of reading and writing; parental authority should be restricted to prevent such cases. Parents also expose their children to small risks of potentially serious harms for their own, rather than the children's, ends, as when the child is made to accompany the parent in the car through the snowy streets in order to pick up a bottle of wine for the dinner guests.[46]

What of more difficult cases? Willard Gaylin has related the story of a friend who took his nine- or ten year-old son for a routine medical examination. Once the examination was complete, the physician turned to the boy and formally asked him if he could take a small blood sample for an epidemiological research project he was conducting. The child, upon learning that the blood donation might hurt, refused to participate, at which point the father ordered that his son comply, which he did. The father, justifying himself to Gaylin, said that he ordered his son to give blood because he wanted to "teach his child that there are certain things one does, even if it causes a small amount of pain, to the service or benefit of others." As Gaylin records the father:

> "This is my child. I was less concerned with the research involved than with the kind of boy that I was raising. I'll be damned if I was going to allow my child, because of some idiotic concept of children's rights, to assume that he was entitled to be a selfish, narcissistic little bastard."[47]

There may be other reasons why we think that the child's participation in non-therapeutic research is permissible or not,[48] but the general point of the father's remarks is that exposing the child to harm is often permissible if it is done in the service of teaching a virtue that the parent finds important. Ideally, the father would have explained the *importance* of helping others to his child with more compassion, but it does seem that exposing a child to a small harm in order to teach him a valuable lesson of life does fall within the bounds of parental authority.

There are limits to the harms to which we can expose a child when the exposure serves no other end than "the virtues." Think of the parents who feel that the virtues of selflessness and of helping others are of the utmost importance in life: Would it be permissible for these parents to consent to the removal of their healthy child's kidney *merely* as a means to teach these particular virtues? Arguably not. Assuming for the moment that the child is old enough to understand how the gift of a kidney to a sibling can be understood as an instance of selflessly helping another, a solid education in "the virtues" seems to be an insufficient justification for subjecting the child to such potentially serious harms. In fact, if the child in this case is told that his kidney was removed *simply* because "helping others is a good thing," it would not be surprising if this child felt downright exploited.

The preceding comments do bring to light the fact that there is a certain amount of leeway that parents are accorded when making decisions that materially affect their child and that have to do with the parents choosing to bring up their child according to their own conception of the good life. But as the examples of non-therapeutic research and kidney donation show us, the freedom of parents to raise their child as they see fit cannot take us very far along the path to justifying decisions that oppose the child's strict interests. As I contended above, there is an avenue worth exploring and it is one that will significantly bear on the issue of intrafamilial child donors; namely, concerns that have intimately to do with one's membership in a family. Presently, I intend to examine the morally salient features of family life before revisiting the question of parental authority and its scope. An examination of the family will, I would claim, give us insights into how better to conceptualize the issue of minor organ and tissue donations.

So, what about the family? Much has been made recently of the claims that can and cannot be made by the family in the context of a patient's medical care. Although these comments have by and large dealt only with the family's claims on competent adult patients,[49] some of the general ideas have implications for the present study. Of the many reasons that the family is important to its members, I will highlight two. First, the family is instrumentally valuable to its members; that is, the family can often be a means to our own chosen ends. When in need, for example, the family can be called on for, say, emotional or financial support; and in the case of dependent children, the family is a means to the important end of survival, even though none of us knew it at the time.

But families are not merely of instrumental value to their members: "Families aren't simply more or less efficient means to some independently specifiable good ends; they are also (at least oftentimes) valuable in themselves."[50] Families are valuable, in other words, independently of the ends (*e.g.*, survival, education, moral lessons) that they facilitate for their members. One of the functions of the family is to "cherish individual members, not for contributions to various ends, but for themselves."[51]

In families, what is important is that family members cherish each other simply for each other's sake, and that being devoted to "the family" and its members is a source of deep meaning and value in our lives and the lives of those around us. Similar sentiments are found in some comments made by Charles Taylor. Reflecting on modern political society, Taylor makes a distinction between two types of "shared significances," a strong type (real sharing) and a weak type (convergence). The weak convergence occurs where, as he put it, "I privately think something is important and you privately think something is important and it turns out that most of us or all of us feel the same." To share something in the strong sense, on the other hand, means that "the good we share in part effectively turns on our sharing; *the sharing in itself is* *valued.*"[52] Nancy Sherman has expressed a similar idea more recently. Attempting to articulate what is important about community participation, Sherman has written:

> One can be in a community and strongly identify with its ends without there being a *sense* of community. In such a case, what seems to be lacking is the pleasure of mutual interaction. A common end may be prized, facilitated by cooperation and collective endeavour, but the goods of mutuality and responsiveness, *that sense of the shared journey*, may simply be lacking. And yet it is this sense that seems to come closest to the value of community *per se.*[53]

I believe that the above bring to articulation much of what is morally important in families —if we recognize the applicability of these comments in the context of society at large, then I believe that we should see these forces at work, *a fortiori*, within the context of an intimate family. There are, I would claim, interests within families that can rightly be called "strongly valued goods,"[54] and that come (to an extent, at least) from the fact that we are engaged in a shared journey with our families. These interests include the interests in the family *qua* family, or family in the abstract —think here of the sense in which the Kennedys might think of "the family"— and the interests in the family *qua* particular individuals, or each member's love, commitment and concern for each other member.[55] The main point here is that the concept of strongly valued goods within the family brings to expression the idea of collectivism in the family; as family members we share significances with other family members in a deeper way than we do with non-family members in our lives.

In addition to familial collectivism, however, other concepts such as favouritism, particularity and nonconsensuality[56] have been ascribed to the family as a result, I would claim, of recognizing the strongly valued goods of our interests to others within the family. Because of the love that exists between family members, we are willing to do much more for our loved ones than we would do for other, non-family members: "Favouritism is part of what it *is* to love, and it takes whatever moral force it has from the value of the love itself. Love, to put it another way, inherently plays favorites."[57] Contrary to many of our associations in life, our family is not freely chosen by us; thus, contrary to associations based on voluntarism where one can expect to be treated the same as everyone else, in the intimate context of a family we are owed more than this: "love and importance, fidelity and solidarity, *all grounded in the fine-grained particulars of lives lived in common.*"[58]

In the family, then, we share ourselves in a very deep way with our fellow family members through our strongly valued commitments. As Sherman has pointed out, "We value creating a shared world, and the mutuality that is defined by our interactions. The pleasure of mutuality and the expansion of self that comes with it is a part of human flourishing."[59] The importance of this mutuality runs more deeply than an expansion of self, however; it may even be described using the stronger language of "union" which involves:

> ... a sense of tracking something with another, of creating a sense of unity through an attunement to each other's moves. The operative virtue here is not respect, nor beneficence, nor even cooperation, though each may enter non-essentially. ... what seems to be at stake is some measure of transcendence; it is a relaxing of one's own sense of boundaries and control. *It is acknowledging a sense of union or merger.*[60]

The family is, then, an association that fundamentally alters our moral landscape and is a well spring of meaning in our lives. A source both of reward and (oftentimes) great burden, we would be very different persons but for our families.

What do these reflections on the family mean concretely, and what implications do they have for the scope of parental authority? I have three points to make here. First, it should now be clearer why I claimed that the best interests calculus is insufficient as a moral framework within the family; simply put, the use of the best interests calculus presupposes a rather impoverished picture of the family as *merely* a collection of individuals. The heart of the best interests standard, embedded as it is in a consequentialist risk/benefit framework, is to calculate the risks and benefits for each individual in the family and to determine which course of action turns up more benefits than burdens on the whole. This view of the family fails to account for those family interests that I have called, borrowing from Taylor, strongly valued goods.

Consider, for example, the suspicion that Buchanan and Brock have with regard to the role of the family in medical decisionmaking. To speak of family interests, or of the family as having its own goals and purposes, is, according to them, "to engage in dangerous reification."[61] When people usually invoke concepts such as "familial interests," claim Buchanan and Brock, they really mean the interests of another individual within the family, and in fact, there are only two circumstances when appeals to the notion of family interests are legitimate:

> (1) The group has expressed some preference through a collective decision-making process (e.g., voting) or (2) there is something that is in the interest of all members of the group individually.[62]

First, (1) assumes that interests are determined through voluntaristic means, and besides the obvious question, Who *votes* in families?, this discounts the nonconsensuality of most deeply held familial interests. Second, although the strongly valued, familial interests of which I spoke above are arguably what Buchanan and Brock are referring to by circumstance (2), they discount this interpretation. Rather, they believe that so-called family interests are "all too likely to serve as a cover for the parents' interests precisely in those cases in which the latter conflict with those of the child."[63] On Buchanan and Brock's reading, then, the parents who argue that it is permissible to subject their child to the burdens of bone marrow harvesting —arguably an act that is contrary to the child's strictly calculated best interests— are really trying to import their own interests into the equation under the guise of the strongly valued interests of helping a loved one and maintaining the integrity of the family. Buchanan and Brock's understanding of familial interests is, unfortunately, rather too thin to capture the strongly shared significances of family life. As Nelson has rightly pointed out, "the moral structure of family relationships cannot merely be subsumed by moral theories such as utilitarianism."[64]

The second point I wish to make relates to the concern that my comments about the family might not be applicable to the children in the family; in other words, in what sense does an eight year-old strongly value the good of familial integrity, or familial sharing? Although many younger children in families do not experience the "shared journey" of family life as deeply as the older family members do, it would be absurd to maintain that there is no deep bond between child and family which engenders the feelings of intimacy that make family life meaningful. And even though it is true that child family members will undoubtedly experience the meaningful intimacies of family life in a very different way than adults, the uneasiness surrounding the discussion of children and strongly valued goods is predicated on the belief that such goods are adopted voluntaristically. As I have argued, this need not be so.

The final point relates to parental authority and its scope. A recognition of the meaningful characteristics of the family will convince us that we do things, and should be expected to do things, for "the family" and for particular family members that we simply would not do for non-family members. Not only are the burdens we bear for the family often far greater than those we would bear for non-intimates, these burdens are most often not generated through consent; rather, such burdens for the most part come with the fact of being a member of a particular family. These points have implications for the issue of parental authority and its scope. Namely, that parents can (and do) legitimately impose burdens on family members, even young ones, simply because they are members of the family. The imposition of some burdens on children (*e.g.*, chores around the house, working in the family business on weekends, *etc.*) is unproblematically accepted as falling within the scope of parental decisionmaking authority. The ease with which we recognize that being part of a family means making sacrifices we would not otherwise make attests to the truth of this proposition.

Not only can parents expect their children to bear greater burdens for the sake of the family, parents can also justify the imposition of these burdens on their children by appeal to family interests that the children might not yet explicitly endorse. In other words, parents and other family members strongly value the intimacy and meaning that the collective journey of family life engenders. As such, the parents may impose burdens on other family members, including children, for many reasons: as a means of maintaining family integrity, or of continuing the family voyage; or in order to help a specific family member. Smith has put it this way:

> These sorts of values, connection, commitment, support, and love can be provided only by a small, intimate group founded on assumptions of mutual reliance and communal cooperation. One name for such a group is family. *And the intrinsic value of its existence is the justification of its general obligations of cooperation and support.*[65]

In so doing, it may often be true that parents are *not* acting to further their child's strictly calculated best interests. Rather, there may be strongly valued family interests being served when children are made to do certain things they might not otherwise be made to do.

§4.4.3 The morality of intimate relationships and the child as donor. At the outset of §4.4, I claimed that if this chapter was to be of any use, I would have to show some sensitivity to the important facts involved in the issue of children as tissue and organ donors. I would like to do that now, and to return to the question that this essay proposes to answer: Is it ever morally permissible to use a child as a tissue or organ donor for the benefit of a family member, and if so, on what grounds is it permissible?

I would like for the moment to consider only young, vulnerable children, say, aged 10 or less.[66] What is important is that the potential child donor is young enough to not really understand the nature of his role in his sibling's proposed treatment much beyond the fact that he "helped" his sibling. That is, although he will understand that his sibling is ill and that he is in a position to help him, the invasiveness and risks of the means used to help his sibling (bone marrow or kidney harvesting) will be understood poorly, if at all. What can we conclude about the role of such a child in the medical treatment of his sibling? In other words, can we justifiably subject the child to the risks of bone marrow or kidney harvesting for the benefit of his sibling?

I believe that an answer to this question will depend largely on the risks to which the donor will be exposed as well as to the expected benefits to the recipient. A transplantation between minor siblings is justifiable, as Dwyer and Vig have recently written,

> when there is a proper fit between the relationship and the risks and benefits. In other words, the justification depends on a *moral match* between the relationship and the risks to the donor relative to the benefits to the recipient.[67]

By "moral match" Dwyer and Vig mean simply that our judgement of the acceptability of the donor risk/recipient benefit ratio is dependent upon the context. Dwyer and Vig are trying to give expression to the idea that burdens we bear for family members will often be greater than those we bear for non-intimates. Given that for our purposes the relationship in question is that between siblings united within a family, is there a "moral match" between the risks to the uncomprehending child donor and the benefits to his recipient sibling?

Consider the case of a proposed bone marrow transplantation. As we have seen (*supra*, chapter 2), the risks which accompany bone marrow harvesting are slight; both the mortality and morbidity rate associated with the use general anæsthetics are very low, and the post-operative morbidities are infrequent and are usually limited to mild, transient pain, as well as treatable infections, both at the site of aspiration. Provided, of course, that the bone marrow transplantation has a reasonable probability of success, I would argue that certain interests at play within the family might be sufficient to justify exposing the child to the risks of bone marrow harvesting.

Despite her possibly limited understanding of the concept of 'bone marrow' and of her role in helping her sibling, we should not assume that the child donor is not subject to the ties that bind her and her family members intimately together. And with this come family interests and their demands, among which should arguably be included acting as a bone marrow donor for a loved one. In addition to this, however, we should not discount the importance that the act of donation can have in her unfolding life narrative. As she grows up she will be told time and again how important she was for her sibling's recovery; and even if her sibling dies despite the bone marrow transplant, it is not hard to imagine how the child will benefit nonetheless from her role in the donation. The child will come to learn about what it means to be a member of the family and the burdens that one accepts for the sake of a loved one.

Moreover, to claim that such a bone marrow donation serves the aggregate best interests of the family simply does not adequately capture the importance of family interests, nor does it capture the real justification for the procedure. Few are the families who will perform a best interests calculation for each member individually and then determine the aggregate best interests of the family in order to determine what is to be done in a particular instance. Thinking of the matter in these terms is to drive a wedge between self and other that, although appropriate for a morality of strangers, obscures what is really at work in the family.

The child, however, does have a voice; and often this voice is one of dissent. As one group of writers have put it: "What if a three- or four year-old potential donor refused to undergo the procedure because he did not like needles? Should his sibling forego transplantation because of the express refusal of the younger child?"[68] That a patient could be allowed to die simply because his sibling was afraid of needles and did not want to go through with the bone marrow donation is something that strikes us as tragically unnecessary. While it is tempting, therefore, to dismiss the dissent of the younger child —"Oh, he'll get over his fears"— I believe that we should treat the dissent of the younger child seriously, but not necessarily as binding. I believe that it is within the scope of parental authority to "force" —I use this word reluctantly— the child to donate bone marrow for the sake of a loved one and for the sake of family integrity largely because of the very low risks which attend bone marrow harvesting, and the very great benefit that can accrue to the recipient. Persistent dissent to the bone marrow harvesting procedure, as some have claimed, *may* have to be treated as binding, but I would argue that such instances would be very rare.[69]

What about a situation of far greater burden? What if the proposed intervention is a kidney transplantation, and an uncomprehending minor is the most suitable donor? I believe that everything that I have written regarding the importance of the family and the values served by shouldering burden for fellow family members holds true in the context of kidney transplantation as well. However, the problem here is whether or not the scope of parental authority is broad enough to justify the imposition of such a heavy burden on a child donor. In other words, is the expected recipient benefit sufficiently great to justify the potentially serious risks that can befall the donor?

Here we are presented with a dilemma fuelled by uncertainty. The invasiveness of the nephrectomy and the severity of the possible risks should make us very sceptical of performing this on an uncomprehending child. Consider the possible risks: death, cardiac arrest, anæsthetic coma, pancreatitis, urinary tract infection, possible late onset hypertension, plus other unknown risks. On the other hand, most nephrectomies proceed without any major complications. And although the recipient may have a more promising clinical outcome with a highly-matched kidney, I think we should consider the uncomprehending minor donor only in cases of absolute necessity — where the death of the sibling is imminent, dialysis is no longer an option and a cadaver donor has not been found. The possible harms associated with the nephrectomy may be too much to ask a child to bear for the sake of the family and for the particular family member.

When children are older, on the other hand, their developing decisionmaking powers should be observed by allowing them some role in the decisionmaking process. Again, the exact age is not the important issue here, although some writers have cited 14 as the age at which children begin to deliberate much as adults do and have developed the relevant capacities for competence in decisionmaking.[70] The older child can, to a greater extent than the young child, explicitly endorse the strongly valued goods of the family as his own. Of course, as I have claimed above, many of the most important family interests and responsibilities are "adopted" by family members nonconsensually; I am not now revoking the importance of these interests in favour only of explicitly endorsed interests, or interests that have been "voted on" as Buchanan and Brock have suggested. Rather, the point is that as a child's mental capacities develop and as she gradually moves towards adulthood, the burdens she is willing to bear can be borne more authentically; that is, an older child who accepts the burdens of donating bone marrow or a kidney to a sibling is, in a strong sense, accepting for herself the belief that part of what it means to be united within a family is to sacrifice one's own strict interests for the sake of other family members. In so doing, the older child makes certain family interests, such as familial devotion and integrity *her own*. Moreover, physicians and parents, in recognizing the developing decisionmaking capacities of the child and in accepting the role of the child in decisionmaking, empower the child to the extent of their capacities.[71]

Given this picture of the older child, I think that it would be justifiable to allow such a child to bear the burdens of both kidney and bone marrow donation. In the first place, the older child is fast approaching adulthood and can accept some of the burdens of family life more responsibly than the younger child, for the reasons given above. As a reflection on this increased decisionmaking ability, certain jurisdictions in North America grant decisionmaking power to legal minors who, although otherwise unemancipated[72], have sufficiently developed decisionmaking capacities[73] and are seeking treatment for certain conditions such as drug or alcohol abuse, sexually transmitted diseases, or for the termination of pregnancy. Thus, emancipated and mature minors are legally permitted to consent to certain medical treatments that carry risk without parental involvement.[74] Arguably, we can draw a parallel between a 14 year-old's ability to consent to the termination of her pregnancy and an ability to consent to, at least, bone marrow donation. That such provisions exist at law, should highlight the fact that older, though legally minor children can often make decisions that carry risk responsibly.

§4.5 Summary

I believe that there are circumstances in which minor children can be exposed to the harms of bone marrow and kidney harvesting for the benefit of a loved one. The justification for imposing such burdens on unconsenting minors is, as we have seen, the family and its interests. These interests have their origins in the intimate context of the family and lay claim to our allegiance and to our efforts. As Schoeman has revealingly put it: "We *share our selves* with those with whom we are intimate and are aware that they do the same with us. Traditional moral boundaries, which give rigid shape to the self, are transparent to this kind of sharing."[75] Similarly, Nelson and Nelson have claimed, "Intimates *belong to each other as well as to themselves*, and this belonging has moral consequences."[76] Indeed, the traditional reliance on the best interests standard when considering the use of minors as tissue and organ donors illustrates the extent to which this reasoning has disregarded the union of family members and their interests, and thus has missed some of the important moral consequences that flow from the family context.

I have all along attempted to avoid the pitfalls of the two following extremes: on the one hand, viewing the importance of family matters with great scepticism, as Buchanan and Brock do, such that the *only* interests that finds expression in moral decisionmaking is that of the concerned party (in our case, the child donor); and on the other hand, an overly romantic view of the family which can result in a thorough disregard for the interests of the child donor and lead his or her exploitation. While some have invoked the child's rights or Kantian principles in an attempt to curb parental authority[77], I am not sure that we need to do that, or whether doing that makes much difference.

Rather, my attempt has been to give an account of the foundations of the family and the claims that the family and particular family members can legitimately make on us, without couching this in the abstract language of rights and duties. I have chosen to speak of concepts such as family interests, strongly valued goods, or union and to invoke ideas such as care, filial integrity or love because I think that family members, when they do feel the pull of the family and decide to donate, are *actually* motivated by such particular and partialist notions; they are not, I would claim, motivated by duty alone, or principally by duty.

One of the principal points that I make in this essay is the following: What we should not do in almost all cases is rule out the donation *a priori* on the grounds that a donation would run counter to the best interests of the unconsenting child. Family members, more than others, should be given a large "normative space" within which to manoeuvre and to discover and act according to their own conception of the good. And this is true for minors as well; although surely moving within a normative space created by their parents, the contours of this space are influenced by their presence as well as that of other family members. To rule out, *a priori*, the participation of minors in intrafamilial donation cases is, I believe, to place (perhaps unnecessary) limits on the good that family members, adult and child, can do for each other.

Endnotes

1. For the moment, the issue of assent/dissent among younger children, as well as the issue of "consent" among older, but legally minor children will be left aside. Below, in §4.4, I will revisit these two issues.

2. This story and quote is taken from: Nelson HL, Nelson JL. *The Patient in the Family: An ethics of medicine and families.* New York: Routledge, 1995 *at* 1. Even when the medical team *is* willing to lie to get a reluctant family member "off of the hook," many prospective donors still feel that they really have no choice but to donate. This has been noted by the University of Pittsburgh transplantation zealot Thomas Starzl. See: Starzl TE. Will live organ donations no longer be justified? *Hastings Cent Rep* 1985;15(2):5.

3. No. 78-17711 *In Equity* (C.P. Allegheny County, Pa. July 26, 1978).

4. No. 78-17711 *at* 2. As quoted in: Huffman FE. Coerced donation of body tissues: Can we live with *McFall* v. *Shimp*? *Ohio St L J* 1979;40:409-440 *at* 409.

5. *McFall* v. *Shimp*, No. 78-17711 *In Equity* (C.P. Allegheny County, Pa. July 26, 1978) *at* 2-3. As quoted in: Huffman FE. *Ibid.*, *at* 413-14. Similar language is found in the *Strunk* case, which dealt with an incompetent adult: "Apparently because of my indelible recollection of a government which, to the everlasting shame of its citizens, embarked upon a program of genocide and experimentation with human bodies I have been more troubled in reaching a decision in this case than in any other," *Strunk* v. *Strunk*, 445 S.W.2d 145 (Ky. 1969) *at* 149 (Steinfeld J., in dissent).

6. *Curran* v. *Bosze*, 566 N.E.2d 1319 (Ill. 1990). See chapter 3, *supra*.

7. There is yet another problem that arises in this context and that falls within the scope of what one might call sound ethical and clinical judgement. If either a suitable live unrelated donor or cadaver donor *has* been found the question arises again, How much of an increase in graft patency or survival that results when you use a live unrelated donor/cadaver donor will be required before you can purchase the better outcome for the recipient at the cost of exposing the child to harm? No attempt will be made to answer this question.

8. There is a problem, however, when the parents are in disagreement over whether to consent to allow their healthy minor child to act as a donor, as was the case in *Curran* v. *Bosze*. As Angela Holder has written: "It is highly improbable that any court would permit a child to be a donor unless both parents are willing to consent if both are available." See: Holder AR. *Legal Issues in Pediatrics and Adolescent Medicine*. Second edition, revised and enlarged. New Haven: Yale University Press, 1985 *at* 171.

9. Since legal minors cannot be placed on unrelated bone marrow donor registries how this situation would arise in practice is unclear. One can imagine a public campaign initiated by the family of a sick child pleading for persons in the community to come forward to donate bone marrow for their child which would then attract the attention of the prospective child donor's parents. That an unrelated child would be a biological match for a stranger would be unlikely; that a child would be a sufficiently good biological match to make the chances of therapeutic success in this case sufficiently high is even more unlikely.

10. A note regarding substituted judgement. Although I will not argue against the doctrine of substituted judgement at length here, I take it that it is wholly inappropriate as a basis for making decisions on behalf of minors. Under the doctrine of substituted judgement, the parents (or the courts) are instructed to decide for the child in the manner that the child would *if he presently had his faculties*. This assumes either that the child *once had* his faculties, which of course is false; or it is really instructing the parents to imagine their child as he *would be* with intact (*i.e.*, adult) faculties, and then to base their decision upon the parents' perceptions of this fictional being of the future. Both alternatives seem incoherent and/or entirely uninstructive. For further critiques of the substituted judgement standard see chapter 3, *supra*.

11. Buchanan AE, Brock DW. *Deciding for Others: The ethics of surrogate decision making*. Cambridge: Cambridge University Press, 1989.

12. *Ibid., at* 123.

13. *Ibid.*

14. The importance of the parents in looking out for the child's future interests is especially marked here. To rely on a child's word about both present and future interests would radically underdetermine what most people consider to be legitimate interests — few, I take it, would accept that "lots of candy and chocolate ice cream" would be legitimate future interests to take account of, even though adults at times often crave for nothing more than this.

15. Buchanan AE, Brock DW. *Op cit., at* 132. This distinction is only *implicitly* made by Buchanan and Brock in the following passage: "If there were sufficiently weighty evidence that the individual did take a strong enough interests in the good of others to justify a decision that runs contrary to the patient's self-regarding interests,..." and "... the determination should focus on the individual's self-regarding interests, not upon his or her alleged interests in the good of others," (*Ibid., at* 133). Strictly speaking, both of these interests should be identified as self-regarding interests. On this, see: Feinberg J. *Harm to Others. Volume 1: The Moral Limit of the Criminal Law.*(New York: Oxford University Press, 1984 *at* 70-79).

16. *Hart* v. *Brown*, 289 A.2d 386 (Conn. 1972) *at* 391; emphasis added.

17. *In re Guardianship of Pescinski*, 226 N.W.2d 180 (Wis. 1975) *at* 183; emphasis added. This case was not discussed above, however, see *supra*, chapter 3, note 48.

18. *Little* v. *Little*, 576 S.W.2d 493 (Tex. 1979) *at* 499; emphasis added.

19. *Strunk* v. *Strunk*, 445 S.W.2d 145 (Ky. 1969) *at* 148; emphasis added.

20. It is useful to note that the degree to which the mentally incompetent person is impaired should alter the way in which we think about such a prospective donor. Although many of the issues that arise in the context of organ or tissue donation by legally incompetent persons are similar whether the prospective donor is incompetent by virtue of age, or by virtue of mental deficiency, the reader should not thereby conclude that there are no meaningful differences in the problems that are raised by these two classes of incompetent persons; nor should they infer that the conclusions that hold true for one group of incompetent persons holds true for the other group as well. Consider, for example: *supra*, chapter 3, note 25.

21. He may, of course, get some pleasure from being told that he helped his sibling. The degree to which this can be characterized as psychological benefit among mentally incompetent persons is surely both highly variable and highly speculative. In a curious bit of reasoning, the mere *possibility* that a mentally incompetent person could miraculously cease to be incompetent and realize that he has done something good for his sibling, has been suggested as a reason that the donation of a kidney *is* beneficial to an incompetent donor —note here that the postulated benefits are not conditional upon the donor *actually* ceasing to be incompetent: "If the incompetent brother should happily recover from his mental illness, he would undoubtedly be happy to learn that the transplant of one of his kidneys to his sister saved her life. *This at least would be a normal response and hence the transplant is not without benefit to him.*" *In re Guardianship of Pescinski*, 226 N.W.2d 180 (Wis. 1975) *at* 182; emphasis added.

22. *In re Guardianship of Pescinski*, 226 N.W.2d 180 (Wis. 1975) *at* 184. The language of *doing* in this passage is odd; the minor donor really is not doing anything, rather, something is being done to her.

23. *In re Guardianship of Pescinski*, 226 N.W.2d 180 (Wis. 1975) *at* 182.

24. Of course, the spouse who remains at home (traditionally, the female) also, in all senses of the term, *works*.

25. Glendon MA. *The New Family and the New Property*. Toronto: Butterworths, 1981 *at* 3.

26. Schoeman F. Rights of children, rights of parents, and the moral basis of the family. *Ethics* 1980;91(4):6-19 *at* 9-10.

27. This is meant to exclude families in which the children are abused or neglected by the parents.

28. My intention in this section is not to offer a comprehensive philosophy of the family; this would take us far beyond the scope of the present essay. For three comprehensive accounts of the philosophy of the family, however, see: Blustein J. *Parents and Children: The ethics of the family*. New York: Oxford University Press, 1982; Houlgate LD. *The Child & the State: A normative theory of juvenile rights*. Baltimore: Johns Hopkins University Press, 1980; and the follow up volume, Houlgate LD. *Family and State: The philosophy of family law*. Totowa, NJ: Roman and Littlefield, 1988.

29. It sounds odd to speak of parents "discharging their duties" of care for their infants; one would be concerned if parents reared their children *only* out of fear that failing to do so might open them up to prosecution under the Criminal Code. That parents are rarely motivated to care for their children out of a sense of legal duty does not, of course, imply that there are no such duties.

To an extent it also sounds odd to speak of the state "allowing" or "entrusting" parents with the duties of child-rearing. It might seem more natural to turn the question around: when is the state justified in intervening into the family? The short answer is in cases of abuse or neglect. Since I have a project different from the issue of justifiable state intervention, it makes more sense for me to leave the question as it is.

30. On the parent child relationship as fundamentally moral, see: Schoeman F. *Op cit.*

31. Often, however, the law's (and society's) reverence for parental privacy/family autonomy has permitted intrafamilial abuses to continue unchecked. On this, see: McMullen JG. Privacy, family autonomy, and the maltreated child. *Marquette L Rev* 1992;75:569-598.

32. Goldstein J. Finding the least-detrimental alternative. *Psychoanalytic Study of the Child* 1972;27:626-41 as quoted in Schoeman F. *Op cit., at* 16.

33. To invoke Rawlsian primary goods as the basics that parents should provide for their children is a common manoeuvre in the literature. See variously: Houlgate LD. *Op cit.*, 1980; Blustein J. *Op cit*; Houlgate LD. *Op cit.*, 1988; Nelson HL, Nelson JL. *Op cit.*; and Ross LF. *Health Care Decision Making for Children*. Unpublished Ph.D. Dissertation: Yale University, Department of Philosophy, 1996.

34. Rawls J. *A Theory of Justice*. Cambridge, MA: Harvard University Press, 1971 *at* 92*ff.*

35. *Ibid., at* 440*ff.*

36. *Ibid., at* 62*ff.*

37. Goldstein J. Medical care for the child at risk: On state supervention of parental autonomy. *Yale L J* 1977;86:645-70 *at* 650.

38. Nelson HL, Nelson JL. *Op cit., at* 36.

39. *Ibid., at* 40.

40. On this, see: Minow M. *Making all the Difference: Inclusion, exclusion, and American law*. Ithaca: Cornell University Press, 1990 *at* 276-77; Estrich S. *Real Rape*. Cambridge, MA: Harvard University Press, 1987; and, more generally, McMullen JG. *Op cit.*

41. This point is inspired by Bernard Williams' well-known criticism of consequentialism, namely, that strict adherence to consequential morality would leave no room for moral agents to pursue personal projects, and hence, would undermine the integrity of the agents — *i.e.*, we would all have to abandon the very things that made us unique (made us *us* and not someone else) in order to bring about the greatest possible good for the greatest possible number.

42. Nelson HL, Nelson JL. *Op cit., at* 63*ff.*

43. *Ibid., at* 77.

44. Schoeman F. Parental discretion and children's rights: Background and implications for medical decision-making. *J Med Phil* 1985;10(1):45-61 *at* 46-7.

45. Nelson JL. Taking families seriously. *Hastings Cent Rep* 1992;22(4):6-12 *at* 8.

46. This example is taken from *Ibid.*

47. Gaylin W. Competence: No longer all or none. In: Gaylin W, Macklin R, (eds.). *Who Speaks for the Child? The problems of proxy consent.* New York: Plenum Press, 1982 *at* 49.

48. On this see the lively and informative debate between Paul Ramsey and Richard McCormick: Ramsey P. *The Patient as Person: Explorations in medical ethics*. New Haven: Yale University Press, 1970, chapter 1; McCormick RA. Proxy consent in the experimentation situation. *Perspect Biol Med* 1974;18(3):2-20; Ramsey P. The

enforcement of morals: Nontherapeutic research on children. *Hastings Cent Rep* 1976;6(4):21-30; and McCormick RA. Experimentation in children: Sharing in sociality. *Hastings Cent Rep* 1976;6(6):41-46.

49. See: Hardwig J. What about the family? *Hastings Cent Rep* 1990;20(2):5-10; Doukas DJ. Autonomy and beneficence in the family: Describing the family covenant. *J Clin Ethics* 1991;2(3):145-48; Loewy EH. Families, communities, and making medical decisions. *J Clin Ethics* 1991;2(3):150-53; Nelson JL. Taking families seriously. *Hastings Cent Rep* 1992;22(4):6-12; and: Mappes TA, Zembaty JS. Patient choices, family interests, and physician obligations. *Kennedy Inst Ethics J* 1994;4(1):27-46.

50. Nelson JL. *Op cit., at* 7.

51. Nelson HL, Nelson JL. *Op cit., at* 75.

52. Taylor C. Hegel's ambiguous legacy for modern liberalism. *Cardozo L Rev* 1989;10:857-70 *at* 861; emphasis added.

53. Sherman N. The virtues of common pursuit. *Phil Phen Res* 1993;53(2):277-99 *at* 290; second emphasis added. Yet another expression of this is given by Blustein: "... in personal relations persons come to define themselves as a unit, not merely as individuals interacting with other individuals. Their interests (or rather some of them) remain the interests of individual persons, yet they are not private, neither congruent nor just convergent, but common and interdependent. ... These interests, which constitute a shared life, are collective." See: Blustein J. *Care and Commitment: Taking the personal point of view.* Oxford: Oxford University Press, 1991 *at* 164-5.

54. This does not imply, however, that I believe that the relationship of the family to its members can be thought of in exactly the same way as the relationship of society to its citizens.

55. Patricia Smith has made the distinction between (*i*) family in the abstract and (*ii*) family as a household of particular individuals, and argued that different family obligations are associated with the different senses of the family. See: Smith P. Family responsibility and the nature of obligation. In: Myers DT, Kipnis K, Murphy CF, Jr., (Eds.). *Family Matters: Rethinking the philosophy of the family.* Ithaca: Cornell University Press, 1993 *at* 41-58.

56. Nelson HL, Nelson JL. *Op cit., at* 63*ff.*

57. *Ibid., at* 67.

58. *Ibid., at* 71-2; emphasis added.

59. Sherman N. *Op cit., at* 278.

60. *Ibid., at* 282; emphasis added. It is interesting to note that Hegel, in his usual obscurantist fashion, captured part of this: "The family ... has as its determination the spirit's *feeling* of its own unity, which is love. Thus, the disposition [appropriate to the family] is to have self-consciousness of one's individuality *within this unity* ... so that one is present in it not as an independent person but as a *member*." See: Hegel GWF. *Elements of the Philosophy of Right.* Wood AW (ed.), Nisbet HB (trans.). Cambridge: Cambridge University Press, 1991 [1821] *at* 199 [§158].

61. Buchanan AE, Brock DW. *Op cit., at* 236.

62. *Ibid.*

63. *Ibid.*

64. Nelson JL. *Op cit., at* 7.

65. Smith P. *Op cit., at* 56; emphasis added.

66. The exact age is not the important point here, I could equally have said aged 9 or less, or aged 11 or less.

67. Dwyer J, Vig E. Rethinking transplantation between siblings. *Hastings Cent Rep* 1995;25(5):7-12 *at* 11; emphasis added. The account given by Dwyer and Vig is similar to my own in highlighting the important role that the family relationship can play in the context of tissue and organ donations by minor children. They fail, as I see it, to give much content to their idea of the "moral match". I believe that in this chapter I have provided this needed content.

68. Levine MD, Camitta BM, Nathan D, Curran WJ. The medical ethics of bone marrow transplantation in childhood. *J Pediatr* 1975;86(1):145-50 *at* 148.

69. Committee on Bioethics. Informed consent, parental permission, and assent in pediatric practice. *Pediatr* 1995;95(2):314-317; and Leikin S. Minors' assent or dissent to medical treatment. *J Pediatr* 1983;102:169-76.

As with the example of blood donation for non-therapeutic research given above by Gaylin, the way in which the parent "forces" the child to comply is surely relevant here. Here we can imagine a study in contrasts. On the one hand, the parents sit down and explain how important this is for the child's sick sibling and for the family as a whole, and they further ensure the child that they will be there to support her every step of the way. The parents listen attentively to their child's concerns and respond to any questions the child has and they arrange meetings with the nurses in the hospital so that the child can become comfortable with the surroundings. Imagine, on the other hand, the parent, in a fit of anger, proclaiming to his frightened and dissenting child: "You're damn well going to do as I say." No further discussion on the matter occurs. I think that the grounds for justifying the imposition of a burden on the child donor are arguably absent in the second case.

70. Buchanan AE, Brock DW. *Op cit., at* 218-25.

71. King NMP, Cross AW. Children as decision makers: Guidelines for pediatricians. *J Pediatr* 1989;115:10-16.

72. The child is declared to be emancipated and thus treated legally as an adult if he or she is: (1) self-supporting and/or not living at home; (2) married; (3) pregnant or a parent; (4) in the military; or (5) declared to be emancipated by the courts. On this, see: Committee on Bioethics. Informed consent, parental permission, and assent in pediatric practice. *Pediatr* 1995;95(2):314-317 *at* 316.

73. They are, in other words, mature minors.

74. On this, see: Holder AR. Minors' rights to consent to medical care. *JAMA* 1987;257(24):3400-02; Landau B. The rights of minors to consent to treatment and to residential care. In: Landau B, (ed). *Children's Rights in the Practice of Family Law.* Toronto: Carswell Legal Publications, 1986 *at* 93-149; and American Medical Association, Council on Ethical and Judicial Affairs. Mandatory parental consent to abortion. *JAMA* 1993;269(1):82-6.

75. Schoeman F. *Op cit., at* 8.

76. Nelson HL, Nelson JL. *Op cit., at* 111; emphasis added.

77. Blustein has spoken of the child's right to self-determination as a shield to parental authority (Blustein J. *Op cit.*, 1982 *at* 163-5), while Ross has argued for parental authority constrained by, among other things, a "modified Kantian agenda by which children must never be treated *solely* as a means, but always, at the same time, as an end-in-themselves, or at least the ends-they-will-become," (Ross LF. Justice for children: The child as organ donor. *Bioethics* 1994;8(2):105-26 *at* 110).