Chapter 9

Medical Hope, Legal Pitfalls: Potential Legal Issues in the Emerging Field of Oncofertility

Gregory Dolin, Dorothy E. Roberts, Lina M. Rodriguez, and Teresa K. Woodruff
G. Dolin (B) George Washington University School of Law, Washington, DC, USA e-mail: greg.dolin@hsc.stonybrook.edu

T.K. Woodruff et al. (eds.), *Oncofertility*, Cancer Treatment and Research 156, 111
DOI 10.1007/978-1-4419-6518-9_9.

http://www.springerlink.com/content/978-1-4419-6517-2#section=759973&page=1

Introduction

The United States annually spends over $200 billion on cancer treatment and research [1]. Over the past several decades, tremendous progress has been made in combating this disease. The 5-year survival rate for cancer has increased from 35%in 1950–1954 to 67% in 1996–2004. Moreover, over the last 40 years, survival rates for childhood cancer have risen from 20% to 81% [2]. However, the very success of new and improved therapies has created a host of problems that were not previously considered. One of the results of the increased rate of post-cancer survival is the commensurate desire of former cancer patients to return to healthy lives, which for many includes having children. Unfortunately for many, this desire is difficult to fulfill, because the medication that succeeded in battling cancer is also quite often toxic to the reproductive organs. Thus, many people are able to live longer lives, yet they feel that their lives are incomplete because they became infertile. Whereas in the past fertility was not even part of the discussion when deciding on the proper cancer treatment, now it is a top concern of many newly diagnosed cancer patients [3]. In response to this concern, medical researchers are investigating several approaches (many of which are described in this book) to preserve cancer patients' reproductive options.

Like many scientific breakthroughs, especially ones dealing with human reproduction, oncofertility enters an area of legal and ethical uncertainty. As the scientific and medical advances in the field of oncofertility are made, researchers, doctors, and patients need to be aware of hidden legal pitfalls and hazards. In this chapter we will discuss some legal questions that are likely to arise in the field of oncofertility. In discussing these questions, we will apply now-existing legal principles in order to develop a framework for answering these questions.

We begin our discussion by identifying the values at stake in the field of oncofertility. These values include the constitutional protection of the rights of women and minors to bear children and to use reproduction-assisting technologies, as well as the feminist critique of gendered expectations that may pressure women to use these technologies.

The medical options already available to patients and those that are being developed are discussed elsewhere in this book, so we will omit the scientific discussion. However,

basic understanding of the medico-scientific principles is useful for fuller appreciation of the legal implications.

After laying out the legal groundwork, we will address the potential legal questions that may emerge as the field of oncofertility develops. Can or must parents consent to a "medically unnecessary" surgery on behalf of a child to preserve her fertility? Who owns the excised tissue and the gametes contained within it? Additionally, legal issues that arise in conducting research on excised tissues for the purposes of future reproduction will be discussed. We avoid making definitive predictions of what the law relating to oncofertility *will* look like. Rather, our purpose is to suggest a framework based on the current state of the law which can help to answer these questions.

What Is at Stake?

Is There a Right to Reproduce?

The right to reproduce is firmly entrenched in American and international law [4, 5]. The United States Supreme Court has declared and reaffirmed the right to bear children in several decisions. For instance, in *Skinner v. Oklahoma* [6], the Court defined this right as "fundamental to the very existence of the [human] race." Subsequent cases involving the right to use contraceptives made clear that substantive due process guarantees the right to reproductive decision-making. In *Griswold v. Connecticut* [7], protecting married couples' right to use contraceptives, the Court described reproductive freedom as "older than the Bill of Rights – older than our political parties, older than our school system. . . and intimate to the degree of being sacred." Similarly, in *Eisenstadt v. Baird* [8], the Court extended this protection to unmarried people, holding that the right to privacy encompasses the "right of the *individual*, married or single, to" make his own decisions as to "whether to bear or beget a child." In a line of cases beginning with *Ohio v. Akron Center for Reproductive Health* [9], the Supreme Court held that minors, no less than adults, possess the right to decide whether to bear a child. In addition to being firmly embedded in US case law, the right to reproduce is also protected under international law. For instance, the United Nations Universal Declaration of Human Rights proclaims that "[m]en and women of full age . . . have the right to marry and to found a family" [10]. The United Nations International Covenant on Civil and Political Rights states that "[t]he right . . . to found a family shall be recognized" [11].[1] The European Convention on Human Rights also adheres to this view [12]. The Cairo Declaration on Human Rights in Islam, adopted in response to the Universal Declaration of Human Rights, states that "[t]he family is the foundation of society . . ." [13]. Though coming to differing conclusions on the ultimate issue of the possession of frozen embryos, both the European Court for Human Rights and the Supreme Court of Israel held that a right to "become a

[1] The United States is a signatory to this Covenant, and has formally ratified it, though with some reservations. 138 Cong. Rec. S8068–71 (1992).

parent" is a fundamental human right [14]. In short, the right to have children is a nearly universally acknowledged and honored right.[2]

Some of the fertility-preserving methods employed in the field of oncofertility rely on scientific advances allowing for gametes to develop in vitro, rather than in vivo. These methods raise the question whether in vitro reproduction enjoys the same status as its much-older counterpart. While significant social and moral issues with respect to assisted reproductive technologies ("ART") arise, current case law and state statutes suggest that the constitutional protection of reproductive decision-making extends to individuals' use of these techniques in order to conceive.

Would it be constitutional for a state to ban or severely restrict the use of ART? Although no court rulings explicitly recognize constitutional protection of a right to assisted reproduction, a review of court cases, statutes, and academic literature provides convincing evidence that US law takes for granted that such a right exists. First, many state statutes recognize the legality of ART and support citizens' access to these services. For instance, an Illinois statute that regulated abortion and other procedures on embryos explicitly declared that "[n]othing in th[e statute] is intended to prohibit the performance of in vitro fertilization" [15]. Louisiana has adopted statutes regulating in vitro fertilization ("IVF") [16, 17], and New Hampshire and Pennsylvania have statutes governing the obligations of sperm donors for IVF procedures, thus recognizing (at least implicitly) the right to use these technologies [18, 19]. The federal government also implicitly recognizes the legality of IVF treatments [20]. In addition, "fourteen states currently require some types of health insurance plans to include coverage of certain infertility services or to make such coverage available" [21]. Thus, while no state explicitly protects a right to use IVF, both state and federal government implicitly acknowledge that such a right exists. These statutes also recognize, however, state and federal power to regulate assisted reproduction, and it remains unclear the extent to which the right to procreate limits such regulation.

Second, court cases have similarly acknowledged a right to use ART. Several courts both in the United States and abroad have adjudicated disputes over ownership of fertilized frozen embryos. While the various courts came to differing conclusions, they all took the underlying right to access ART as a given. For instance, in *Davis v. Davis*, Tennessee's highest court implied – without explicitly holding – that the right to procreate by the means of IVF is within the ambit of the constitutional right to privacy [22]. The New Jersey Supreme Court adopted the same reasoning in *J.B. v. M.B* [23]. The New York Court of Appeals, while not explicitly endorsing *Davis,* advised parties to IVF to enter

[2] To be sure, the right to bear children is not an unfettered one. Some courts have held that the state may limit a person's ability to reproduce in certain circumstances such as imprisonment or flagrant disregard toward child support obligations. See, e.g., Gerber v. Hickman, 291 F.3d 617 (9th Cir. 2002) (en banc) (holding that prison inmates lose their right to reproduce); State v. Oakley, 629 N.W.2d 200 (Wis. 2001) (upholding a condition of probation requiring a "dead beat" to avoid having another child).

into agreements on disposition of zygotes, thus treating ART as a legal means of reproduction and perhaps taking for granted its constitutional protection [24].[3]

At the same time, some courts have placed limits on individuals' right to use ART. In *In re Baby M*, for example, the New Jersey Supreme Court voided as against public policy a surrogacy contract between the Sterns and the birth mother, Mary Beth Whitehead, when she decided to keep the baby [25]. Thus, while the court implicitly acknowledged Mr. Stern's right to use IVF, it held that the constitutional right to reproduce did not encompass state enforcement of surrogacy contracts.[4] Nor have courts held that the right to use ART includes a claim for state assistance to pay for these services. Louisiana and Nevada explicitly exempt health insurance plans from having to cover IVF in statutes that mandate coverage for other reproductive health services, and many states do not provide infertility treatment in their public medical assistance programs [21]. These limits on the right to access ART fit within the current US Supreme Court interpretations of reproductive liberty as a negative right against state interference [4, 21].[5] In other words, while states are free to mandate insurance coverage of ART, the Constitution does not require it.

Although the right to access ART, if one can afford it, is accepted by legislatures and courts, women's use of these technologies remains controversial. On the one hand, some scholars see access to assisted reproduction as extending women's reproductive liberty [5, 26]. Technologies that help women have children enhance the choices they have to fulfill their reproductive desires. In the context of oncofertility, it can also be argued that techniques that restore fertility to female cancer survivors place women on equal footing as men, who are easily able to store semen for future use. Oncofertility can be viewed as a gender equalizer that gives women and girls the same reproductive options as men and boys. On the other hand, feminists have long questioned the gendered forces that lead many women to use ART [27, 28]. They point out that women's desire to bear children is influenced by the stigma of infertility and the expectation that all women will become mothers. Added to this is the desire to have a genetically related child. Some women feel a duty to undergo the expense and physical trauma entailed in IVF, rather than remaining childless or adopting a child, in order to be acceptable to a male partner and the wider society. Girls whose ovaries have been preserved may feel added pressure to become mothers because of the effort and expense that went into the procedure. Although many

---

[3] See Also *In re* Marriage of Witten, 672 N.W.2d 768 (Iowa 2003); Litowitz v. Litowitz, 48 P.3d 261 (Wash. 2002); A.Z. v. B.Z., 725 N.E.2d 1051 (Mass. 2000). 337 (2d Cir. 2003)) [21].

[4] John Robertson argued that procreative liberty includes a constitutional right to state enforcement of surrogacy agreements [5]. For a critique of Robertson's position, see Roberts DE. Social Justice, Procreative Liberty and the Limits of Liberal Theory: Robertson's Children of Choice. *Law & Soc. Inquiry*. 1995; 20:1005–21.

[5] Two federal appellate courts have rejected the claim that health plans that exclude infertility treatments violate Title VII of the Civil Rights Act of 1964 or the Pregnancy Discrimination Act (Krauel v. Iowa Methodist Med. Cent., 95 F.3d 674 (8th Cir. 1996); Saks v. Franklin Covey Co., 316 F.3d 337 (2d Cir. 2003)) [21].

believe that access to ART is essential to reproductive freedom, others see it as reinforcing unjust expectations about women's reproductive roles.

This review of statutes and court decisions shows that US law currently acknowledges that procreative liberty encompasses, subject to some degree of state and judicial regulation, the right to use ART. Having established this, we now proceed to the discussion of unsettled legal issues that may affect oncofertility in practice, and thus the treatment options given to patients.

What Are the Reproductive Rights of Minors?

Generally speaking, minors have the same reproductive rights as adults, except that states have greater power to regulate the conduct of minors. In *Bellotti v. Baird*, the Supreme Court held that a requirement of parental *consent* to abortion, without a judicial bypass provision, was unconstitutional. Although the Court subsequently has been more solicitous of legislative attempts to interpose adult involvement in the minor's abortion decisions, it has never allowed any state to legislate a scheme under which a minor's decision could be vetoed by a parent (unless such a "veto" is also sustained by an impartial judge) [29]. Additionally, most states permit minors to use contraceptives without seeking adult permission [30, 31].

With respect to deciding to bear a child (as opposed to deciding to terminate a pregnancy), minors' rights are even broader. The age of consent in many states is well below the age of majority (especially when both participants are minors). No state permits any third party to require a minor to get an abortion should the minor become pregnant. In other words, if a minor decides to bear the child, the decision is hers alone. Finally, as discussed below, parents cannot deprive minors of future reproductive capacity, absent compelling need *and* a court order. In short, a minor's liberty to determine his or her own reproductive future is constitutionally protected from restraint except in narrow circumstances that are subject to judicial review. Minors enjoy the same constitutional protection of their reproductive rights as adults do, even if exercising some of these rights (due to the limitations of biology) is deferred until they mature.

The Legal and Moral Questions

Who Can Consent to a Medical Procedure and What Are the Limits?

As with any other medical procedure, the patient must freely and voluntarily consent to undergo ovarian tissue cryopreservation in order for the protocol to be legally (and morally) employed [32, 33]. Any medical manipulation of the patient without such consent, under our laws and traditions, constitutes battery (even if medically beneficial to the patient).

Generally speaking, a competent adult can consent to almost any legal medical procedure, including one that will permanently alter his or her reproductive capacities [34–36]. Thus, adults are free to consent to tubal ligation or vasectomies, even though

these procedures are most often irreversible, and thus will permanently limit reproductive capacity of the patient. Conversely, as discussed below, competent adults can consent to procedures that will preserve or enhance their reproductive capacities. Thus, when the oncofertility patient is a competent adult, she can legally and ethically decide for herself whether or not she wants to undergo an invasive procedure in hopes of preserving future reproductive capacity.

Consent, while a sine qua non of ethical medical practice, is not the only consideration. The first principle of medicine is "first, do no harm." In other words, the physician ought not perform procedures or prescribe treatment that carries risks, but no identifiable benefits. This does not mean that experimental treatments are out of bounds, but, rather, that prior to asking for the patient's consent, physicians must assure themselves that the treatment offered carries more potential medical benefits than harms.

With respect to minors, the question of consent becomes more complicated. In most circumstances, parents (or legal guardians) are invested with legal authority to make medical decisions for their minor offspring and generally can choose when, whether, and from whom to seek care for their minor children [37].[6] This discretion is given to parents for good reason. As the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research observed:

> [A] family member ought usually to be designated as surrogate to make health care decisions for an incapacitated patient in consultation with the physician and other health care professionals:
>
> (1) The family is generally most concerned about the good of the patient.
> (2) The family will also usually be most knowledgeable about the patient's goals preferences, and values.
> (3) The family deserves recognition as an important social unit that ought to be treated, within limits, as a responsible decisionmaker in matters that intimately affect its members.
> (4) Especially in a society in which many other traditional forms of community have eroded, participation in a family is often an important dimension of personal fulfillment.
> (5) Since a protected sphere of privacy and autonomy is required for the flourishing of this interpersonal union, institutions and the state should be reluctant to intrude, particularly regarding matters that are personal and on which there is-. [sic] a wide range of opinion in society [38].
> (6)There are exceptions to this rule. Parents cannot refuse life-saving treatments, such as blood transfusions, and may not deprive their children of medical attention when such deprivation is tantamount to child abuse. However, with respect to routine procedures, the choice lies with the parents.

The United States Conference of Catholic Bishops similarly notes that "family members and loved ones" are usually "in a position to know best the patient's wishes" [39]. In addition to these moral and ethical observations, American courts have held that parents have a constitutional right to bring up children as they deem best without interference by the state, absent a compelling state interest to the contrary [40–43].

---

[6] There are exceptions to this rule. Parents cannot refuse life-saving treatments, such as blood transfusions, and may not deprive their children of medical attention when such deprivation is tantamount to child abuse. However, with respect to routine procedures, the choice lies with the parents.

The parent's right to decide on a child's treatment is not absolute. Unlike a competent adult who can choose to reject any treatment for any or no reason, a parent cannot reject a medically necessary treatment on behalf of his child. Parental decisions regarding medical treatment are limited by the principle that parents must act in the best interest of the child [44–46]. Thus, for instance, a parent may not decline a blood transfusion on behalf of his child, even if both the child and the parent hold religious views that prohibit blood transfusions [47–49]. Similarly, parents cannot consent to enroll a child in clinical research "unless it is intended to promote the health of the population represented by the potential subject, [and] the research cannot instead be performed with competent persons" [50]. Furthermore, parents are limited in their ability to consent even to experimental treatment of the minor by two considerations. "First, if the treatment is not medically necessary for the minor, it must not be unreasonably harmful. Second, the treatment must be to the benefit of the minor, and not just to the benefit of the minor's parents or other family members." [51, 52]. These limitations are not surprising if one keeps in mind the overarching requirement that in deciding on the course of treatment, parents must act in the child's best interest.[7]

In addition to obtaining parental consent, it is often useful to seek the child's input into the treatment decision. First, such input may carry legal weight. Second,

> [s]eeking the assent of a minor who is not legally authorized to consent demonstrates respect for the decision-making skills of a nonautonomous individual to the extent that he or she is able to participate in the decision. This is particularly relevant for adolescents who are cognitively mature but below the age of legal majority and still dependent upon adults for their basic health care decisions [53, 54].

Third, seeking minor's assent may be a prerequisite to administering the treatment effectively because it ensures that the patient is compliant.

Thus, when dealing with pediatric patients the simple formula of "'efficacy of treatment' plus 'patient's consent' equals 'administering the treatment'" does not hold. In pediatric cases, in addition to assuring themselves of the treatment's benefits, physicians must also make sure that they seek parental consent and the child's assent (where practicable). These considerations ultimately are subject to a judicial determination of the best interests of the child.

Are There Limitations to Proxy Consent in the Reproductive Context?

As the above discussion demonstrates, although parents are generally permitted to make medical decisions for their minor children, these decisions must be in the best interests of the child. In the area of sexual health and reproduction, parents' decisional rights are further limited. For instance, courts have held on numerous occasions that parents cannot veto a minor's decision to seek an abortion. Numerous states have also enacted

---

[7] When there is room for a legitimate difference of opinion as to which treatment is best, the state defers to the parental choice. Parents are, however, precluded from choosing a treatment that has no identifiable benefits to the minor [37].

legislation that allows a minor to seek treatment (or preventative measures) for pregnancy and sexually transmitted disease without parental involvement or consent. There are weighty reasons why reproductive decisions are excluded from otherwise nearly plenary parental authority to make medical decisions on behalf of their offspring. First, because decisions that affect the reproductive capacities of minors necessarily interfere with "one of the basic civil rights of man," they must be heavily scrutinized and sometimes disregarded. Second, it may be more likely that parental involvement in a minor's decisions on such sensitive issues as sexual activity and pregnancy will not serve a minor's best interest.

In exploring the limits of parental authority over reproductive and sexual health decisions of minors, it is useful to look at the jurisprudence governing four procedures – male circumcision, female genital cutting, sex assignment surgery, and sterilization. All four are elective procedures,[8] but all are not treated in the same way by the legal system [55]. Looking at the differences in the leeway permitted to parents in each of those circumstances, and the underlying reasons for those differences, can help in constructing a framework within which questions about the legal treatment of oncofertility can be answered.

Male Circumcision

Male circumcision involves removal of the foreskin of the penis. It is a procedure usually performed on a newborn child, sometimes for religious or cultural reasons. Following World War II, the practice of circumcision became quite common in the United States. Parents routinely consent to the procedure and it is routinely performed. Lately, however, the practice started drawing criticism as being incompatible with the child's right to bodily integrity and autonomy [56, 57]. In 1999, the American Academy of Pediatrics issued its position statement on circumcision, recommending that doctors should not routinely advise parents to seek circumcision of their sons, but should, at the same time, yield to parental request for the surgery [58]. Despite the increased criticism, male circumcision remains legal.

For instance, in a 2008 case involving a dispute between divorced parents over the decision to circumcise a minor male child, the Oregon Supreme Court held that the custodial parent has legal authority "to make medical decisions for his or her child, *including decisions involving elective procedures* and decisions that may involve medical risks" [59]. The court explicitly noted that "although circumcision is an invasive medical procedure that results in permanent physical alteration of a body part and has attendant medical risks, the decision to have a male child circumcised for medical or religious reasons is one that is commonly and historically made by parents in the United States." The court did limit parental authority somewhat by directing the trial court to examine the views of the minor (12-years-old at the time) and take them into account. In *State v. Baxter* [60], the Washington Court of Appeals noted that "ritual circumcisions . . .have been performed for thousands of years and have *never been held contrary to public*

[8] In some cases, male circumcision may be medically necessary, but those constitute a minority of all circumcisions performed in this country.

policy." Courts in other states, in addressing various claims of medical malpractice and improper informed consent for the circumcision procedure, have uniformly assumed that a properly performed circumcision after a proper informed consent by one of the parents is fully consistent with the law [61–63].

Female Genital Cutting

By contrast, consider a procedure performed on minor females commonly referred to as "female circumcision" or "female genital cutting," which involves "partial or total removal of the external female genitalia or other injury to the female genital organs *for non-medical reasons"* [64]. Like male circumcision it may be performed for religious or cultural reasons, and like male circumcision it is "an ancient cultural or social custom" [65]. Unlike male circumcision, however, female genital cutting is universally viewed (in the American legal system) as a procedure to which parents cannot legally consent.

For instance, in 1996, Congress passed the Criminalization of Female Genital Mutilation Act, which makes it a crime to perform the procedure on a minor.[9] In enacting the statute, Congress found that "the practice of female genital mutilation often results in the occurrence of physical and psychological health effects that harm the women involved." This finding is supported by a similar statement of the World Health Organization. A number of states have enacted similar prohibitions of the practice.[10] Thus, unlike male circumcision, which is generally considered to be a safe procedure with some possible medical benefits, the female genital cutting is viewed in this country as both non-beneficial and harmful.

Sex Assignment Surgery

A third case of elective sexual surgery is sex assignment surgery performed on minors. Studies show that nearly one out of every two-thousand children born in the United States is born with ambiguous genitalia [66]. An estimated one to two hundred pediatric sex assignment surgeries are performed each year [67]. The sexual assignment surgeries for children with ambiguous genitalia became an accepted standard of care in the 1970s. Most of these children underwent surgeries to create external female genitalia, and were raised as girls. Since the surgeries were performed on minor children, parents were the ones consenting to the procedure. Although there have been no definitive court decisions, in 1996 the American Academy of Pediatrics supported the idea of elective sex

---

[9] The statute provides that (subject to certain medical necessity exceptions) "whoever knowingly circumcises, excises, or infibulates the whole or any part of the labia majora or labia minora or clitoris of another person who has not attained the age of 18 years shall be fined under this title or imprisoned not more than 5 years, or both." Note, however, that an adult can consent to this procedure for herself. This is in line with the general rule that an adult can consent to virtually any legal medical treatment or procedure. (Criminalization of Female Genital Mutilation Act, 18 U.S.C. § 116 (2000)).

[10] CAL. PENAL CODE § 273.4; DEL. CODE ANN. tit. 11, § 780; 720 ILL. COMP. STAT. 5/12-34 (2002); MD. CODE ANN., HEALT–GEN. § 20-601;MINN. STAT. ANN. § 609.2245; N.Y. PENAL LAW § 130.85; N.D. CENT. CODE § 12.1-36-01; R.I. GEN. LAWS § 11-5-2(c)(3); TENN. CODE ANN. § 39-13-110;WIS. STAT. ANN. § 146.35.

assignment surgery and recommended that it occur before the age of two-and-a-half years [68].

In the last decade, serious concerns have been raised about the efficacy of the sex assignment surgeries and the consequences such surgeries have on the patients. For instance, cases have been reported where the children who had sex-assignment surgery grew up unhappy with and confused about their assigned gender, and with psychological problems stemming from these feelings. The discovery of these harms, and the realization that sex-assignment surgery forecloses the "[c]hild's [r]ight to an [o]pen [f]uture," has led some experts and advocates to question the morality of parents consenting to sex-assignment surgery without any input by the children themselves. Nonetheless, the current standard of practice in the medical profession is to permit, and even to encourage, parents to quickly decide whether to assign a specific sex to a child with ambiguous genitalia. In the absence of statutes or court decisions to the contrary, this remains a legal practice, even though it permanently determines a child's sexual identity and the way the child will lead his or her life.

Sterilization

A final case to consider is the parental decision to sterilize a child. Some parents wish to sterilize a daughter who is severely developmentally or mentally disabled because they believe that child bearing is not in the daughter's best interest, in part because she is unlikely to be able to care for her child, or perhaps even to understand the nature of pregnancy and childbirth [69]. Nonetheless, in most states, parents cannot make this decision on their own, even if the medical professionals agree with and recommend this course of action [70, 71]. Instead, most states require an independent judicial determination of the best interest of the child sought to be sterilized. The courts and legislatures have viewed sterilization "as an extraordinary measure which is to be decided by a court and undertaken only pursuant to court order" [72]. That is so because "[c]onsent by parents to the sterilization of their mentally retarded offspring has a history of abuse which indicates that parents, at least in this limited context, cannot be presumed to have an identity of interest with their children" [76, p. 370]. Generally, courts also require that there be "clear and convincing evidence" – a very high standard – showing that sterilization is in the child's best interests and that it is the least intrusive method of controlling the child's reproduction [73–76].

Variations in Parental Consent Requirements

A common thread runs through the four situations just reviewed. It appears that the parental right to consent to surgery involving reproductive or sexual organs is highest when the procedure has identifiable (even if controversial) medical benefits and does not threaten the health or future reproductive choices of the child. Additionally, historical traditions as well as contemporary cultural and professional value judgments play a significant role in the acceptance or rejection of a procedure. Thus, parents are given virtually unfettered authority to consent to male circumcision because there are identifiable medical benefits to the procedure and because the procedure has been part of

the Western tradition for close to 5000 years. Similarly, parents can consent to sex assignment surgery because the mainstream medical profession believes this surgery is necessary for a child's normal psychological and emotional development, despite contradictory evidence from recent studies. This perceived medical benefit is tied to dominant US social norms which dictate that individuals must have unambiguous external genitalia and sexual identities.

On the opposite side of the legal spectrum, female genital cutting is considered to offer no medical benefit of any kind, is foreign to Western traditions, and carries a high medical risk to the subject. Hence, parents are flatly prohibited from consenting to this procedure. The decision to sterilize an incompetent girl lies somewhere in between. Although the procedure arguably provides medical benefits by preventing a possibly harmful pregnancy, sterilization runs counter to US traditions that encourage reproduction and individual liberty. It also conjures up the sordid history of compelled sterilization of "feeble minded" and disabled persons during the eugenics era, which was discredited after World War II. Therefore, parents' request for sterilization is subject to approval by an independent judge.

How Does Current Law on Proxy Consent Apply to Oncofertility?

The legal treatment of parental consent regarding the four elective surgeries discussed above can be used to create a framework for analyzing parental consent in the context of ovarian tissue cryopreservation.

The first consideration is the age of a child. If the child is still a minor but of an age at which she can comprehend some issues about future reproduction, she should be consulted. As the Oregon Supreme Court noted in *In re Marriage of Boldt*, at a certain age, decisions dealing with permanent alterations of the body may affect the relationship between the child and parent and could have a "pronounced effect on parent's capability to properly care for" the child [77]. Furthermore, other courts have recognized that mature (though not emancipated) minors, can participate in decisions about their healthcare, even if the decision is contrary to the commonly accepted medical practice [78–80]. Additionally, and as described above, courts and legislatures have long permitted minors to make decisions involving reproduction or sexual health with a reduced level of parental control over those decisions. Thus, in our view, to the extent possible, the views of the child must be solicited and, though not dispositive, be given due weight.

The second issue to be taken into account is the question of how much sexual function is likely to be retained post-surgery. For instance, if the procedure involves the removal of only one ovary, with the other remaining in place and being counted on to provide proper hormonal balance in the later years, there may be less concern than in cases where both ovaries are to be excised or where the ovary to be excised is the only healthy one. In the former cases, the risk to the patient is rather small, and the change in natural unassisted reproductive and ancillary sex functions is similarly small (though appreciable) [81]. In the latter cases, on the other hand, the chance of losing unassisted function is certain, and

the child will need perpetual hormone replacement therapy [82]. In a situation such as this, a very careful balance must be made between the uncertain potential for future biological offspring versus the real and definite consequences of losing an organ that provides proper hormonal balance – and perhaps also reproductive function.

The third consideration is the size of the putative benefit of undergoing the chosen oncofertility procedure. It is worth remembering that at this stage the science of ovarian tissue removal for the purposes of future reproduction is at its infancy. No live births in humans have yet been reported following excision of an ovary and subsequent in vitro follicle maturation and fertilization [83].[11] However, live births in humans have been reported following excision of an ovary from tissue transplants and in vitro fertilization of available mature eggs [84–87]. It should be noted, that as of this writing, successful maturation of a human follicle to a mature egg capable of reproduction has been reported. Still, with regard to the preservation of human fertility, the protocol in question is at the early experimental stages. Importantly, since patients who are 5 or 6 years old today will not be in a position to have children for another 15–20 years, it may well be that by then, the oocyte maturation process will be well established and will result in a level of success not below that which is expected for "regular" IVF protocols. Nevertheless, it must be recognized that at the present day, successful preservation of reproductive ability via ovarian tissue removal and storage is still under development.

The last issue to consider is the purpose of the parent's decision to subject the child to the ovarian tissue removal. To the extent that the parental decision is purely about preserving the child's future options, it is likely to be more acceptable to the legislatures, the courts, and the general public. As discussed above, much turns on whether the proposed medical procedure fits within US social traditions and norms. Because the ability to reproduce is generally valued in US society and is protected by the Constitution, preserving reproductive options is likely to be considered highly beneficial. In fact, the primary critique of the procedures discussed in these previous section is that they ignore "the [c]hild's [r]ight to an [o]pen [f]uture." Oncofertility procedures can be seen as preserving this right.

It can also be argued, however, that parents who seek ovarian excision & cryopreservation for their daughters are steering the child's future decisions toward child bearing. A child who undergoes ovary removal and preserves her ovarian tissue for a number of years may as a woman, feel enormous pressure to use the stored tissue. It provides a powerful reminder throughout the rest of her childhood and early adulthood of parental and societal expectations that she should one day bear children. Nonetheless, even if parental choices end up influencing the future choices of minors, such influence is legally permissible, as can be evidenced from a variety of decisions upholding parental rights to raise their children in a manner they deem appropriate.

On the other hand, consider the situation where the child has very little hope of recovery, yet the parents still wish to subject her to the ovarian tissue removal procedure in the

[11] However, studies on mice have resulted in live births. *See* Xu M, et al. Tissue-Engineered Follicles Produce Live, Fertile Offspring. *Tissue Engineering*. 2006; 12:2739–2746.

hope of having a genetic grandchild from their soon-to-be-deceased child. When analyzed within the above-suggested framework, this hypothetical leads to a different result. In this situation, it cannot be fairly said that parents are preserving reproductive capacity and decisions that the child can exercise upon reaching the age of majority. The parents are preserving *their own* option of having a grandchild, but not their child's options (since the child is not likely to survive). In these circumstances, a court might decide that the parents are not acting in the best interest of the child, but are subjecting her to unnecessary medical procedures that carry no benefit either now or in the future.

Is Failing to Preserve Fertility the Same as Active Sterilization?

The reverse side of the question of whether parents *can* consent to the ovarian tissue cryopreservation is the question of whether they *must* consent to it. Do parents have a duty to preserve their child's fertility if ovarian tissue cryopreservation is available? Do children have a right to the procedure even if their parents do not wish to consent to it? Although we cannot at this stage give any definitive answers, we will explore parents' potential legal obligations and outline the issues that ought to be taken into consideration when resolving these questions.

As discussed previously, parents are generally given wide latitude in deciding what constitutes appropriate medical treatment for their offspring. However, that latitude is circumscribed by the requirement that parents act in the best interest of the child consistent with not only the family's values and morals, but also with good medical practice and with "society's basic values."

The premise underlying parents' right to consent to ovarian tissue cryopreservation is that the procedure preserves the "basic" societal value of reproductive choice. It can be argued that children for whom parents give consent will be in a better – if not exclusive – position to exercise this choice compared to children whose parents did not consent. According to this view, parents who choose not to consent are depriving their child of her right to reproduce. In other words, it can be argued that parents' refusal to consent to a viable ovarian tissue cryopreservation is, in effect, no different than the parents' decision to sterilize their child – a decision that parents are not permitted to make without judicial approval. On the other hand, sterilization involves active medical intervention, whereas declining to consent to the ovarian tissue cryopreservation is passive non-interference. Whether this makes a difference in the legal outcome depends on a judgment about the moral equivalency of action and inaction in these cases [88]. That calculus may be affected by the eventual degree of success of ovarian cryopreservation.

In contemplating what the correct answer to the above dilemma should be, it is useful to weigh the factors discussed in the preceding section – the balance of medical risks and benefits, the societal acceptance of the practice, the effect on the child's "open future," and the success rate of the treatment.

To the extent that the minor in question can rationally consider her options and express her preferences accordingly, that should mostly be the end of the matter. Courts and

legislatures routinely defer to mature minors' decisions on reproductive matters. Indeed, courts occasionally defer to minors even on life and death matters if the minor's decision is in accord with that of the parents, and if the minor is sufficiently mature. It stands to reason then that if minors can choose to terminate or to continue with pregnancy, their wishes will most likely be similarly honored with respect to the decision to preserve future fertility. Of course, this "easy" solution does not obtain when the minor is unable to rationally consider the various choices and come to an informed decision. Thus, the remaining two factors need to be considered.

First, the surgical risk of excising an ovary is minimal. In most cases, the procedure can be performed laparascopically. Although certain risks of infection and error are present, it is no greater than risk associated with any other surgical procedure (e.g., tonsillectomy). The low risk of the procedure, coupled with the low burden that it imposes on the minor, then militates toward the position that the procedure ought to be performed. On the other hand, the risk of being left without the ovary is significant. As discussed previously, loss of an ovary alters the hormonal balance and reduces the chances of in vivo pregnancy. This very real risk counsels against performing the procedure.

Second, presently, the success rate of using frozen ovarian tissue to obtain a live birth is speculative at best. But even if it were to become as successful as established IVF procedures, the success rate would still be quite low. If techniques using frozen ovarian tissue rise to the same level of success as IVF, it will no doubt be a tremendous achievement and a huge leap forward in terms of reproductive options available to young women stricken with cancer. That said, a 30% level of success may be insufficient to definitively require parents to take one or another course of action. On the other hand, if techniques using frozen ovarian tissue achieve significantly higher success rates (e.g., 80–90%), a much stronger case could be made that depriving the child of an opportunity to decide for herself whether or not to bear children later in life is a violation of the child's best interest and ought not be permitted.

The three factors outlined above, however, are not exhaustive, for they do not take into account individual family values that the parents hold and are likely to impart to their child. Parents are entitled to take their values into account in making medical decisions for their children. Moreover, the parents may place a higher priority on their child's current health than on their child's ability to become pregnant in the future. They may also oppose the use of reproduction-assisting technologies for religious, ethical, or cultural reasons. There is no doubt that the values imparted during the child's upbringing play a large role in the child's own decisions during adult life. Thus, for example, a child may grow up in a family that opposes procreation and instead supports adoption (because, say, they believe that the world is overpopulated). In that hypothetical family, the ability to reproduce in the future would not be particularly valued. Because this value is likely to be imparted on the child (who, given the hypothetical, would likely have been adopted), it is more likely than not that once grown, the child will not place a great premium on the ability to reproduce.

It is no answer to say that ovarian tissue cryopreservation simply preserves choice and does not actually force anyone to reproduce should they not want to. Subjecting the child to these medical procedures carries certain finite risks. It also is potentially distracting from the major issue facing the family – saving that child's life. Thus, the protocol is neither cost- nor risk-free. And the benefit that the protocol provides for the child of the hypothetical parents described above is, at best, questionable. Thus, deeply held family values should also be seriously considered and taken into account in deciding whether parental decisions not to consent are subject to judicial override.

The balance of factors, then, *at present*, counsels against disregarding parental wishes to forego ovarian tissue cryopreservation. However, as we stated in the beginning of this subsection, we cannot, with any confidence, predict how courts and legislatures will respond to this dilemma should it ever arise. By outlining this potential dilemma and discussing the factors that are likely to influence the answers, we are hoping to provide practitioners, patients, and the public a framework for the discussion of these questions.

Who Controls the Fate of the Excised Tissue While the Patient Is Alive?

Once the gametes (whether sperm or ova) are harvested and stored (in whatever form) there is a question as to who controls the usage of this stored material. In cases of adults, the answer is clear. The control resides with the progenitor herself. The right to control the fate of one's gametes, whether these gametes are intra- or extra-corporeal, is firmly established in the law. As the Tennessee Supreme Court held in *Davis*, "the existence of the right [of procreational autonomy] itself dictates that decisional authority rests *in the gamete-providers alone*." Thus, a clinic cannot do anything with the stored gametes to which the progenitor has not agreed.

Children are at a disadvantage in this situation because they may not be able to express their wishes as to any disposition of the stored gametes, and to the extent that they are able to express them, such expression may not be legally binding while the children are minors. Nonetheless, we are of the view that the only people who should have the authority to decide the disposition are the children themselves, when they reach the age of majority. We come to this conclusion for several reasons.

First, the very premise of oncofertility treatment (whatever form it may take) is to preserve the patient's choices on whether or not to have children. Any decision by the guardian to donate or otherwise dispose of the child's gametes would vitiate the child's ability to make future choices. Hence, the initial procedure to preserve gametes would become useless, and therefore, in retrospect, would be improper, since it would serve no medical purpose whatsoever. Second, it is well established that children are not proper sources for live organ or tissue donation [89–95].[12] Therefore, parents should not be able to donate the child's gametes, just like they cannot donate a child's kidney or blood. Third, the parents' decisions with respect to the minors' medical treatment are limited by the requirement that the parents act in the best interest of the minor. When parents choose

[12] There is a very narrow exception for intra-family donations by minors when such a donation is necessary to save the life of another family member. Even blood donation by minors is limited.

to dispose of minors' gametes, it is hard to see how they are acting in the minors' best interest. At best, such a decision neither advances nor detracts from minors' interests, and at worst, it runs directly contrary to those interests.

Finally, as we discussed above, parents are not permitted, without good cause and court approval, to forcibly sterilize their children. It seems to us that the prohibition applies whether the child's reproductive capacity is inside or outside the body. Any decision by the child's guardian that would destroy or significantly limit a child's existing reproductive capacity cannot be honored without the court's consent. Moreover, permitting someone other than the child to decide would create a dangerous risk of exploitation. For these reasons, we believe that once gametes are stored, the only person who can dictate their ultimate disposition is the donor. In those cases where the donor is a minor, the gametes must be stored until such time as the minor can legally direct their use or disposition.

Who Controls the Fate of the Excised Tissue When the Patient Is Dead?

A more perplexing question regarding the ownership of excised and stored tissue arises if the patient dies. As discussed above, while the donor is alive, there is no question that she retains ownership of her tissue (unless she donated it to someone else) and that she can dispose of it as she wishes. The sad fact, however, is that far from all oncological patients win their battle with cancer. Once the patient dies, who should decide the disposition of the tissue that she left behind?

The ovarian tissue cryopreservation protocol at Northwestern University presently employs a consent form where the patient agrees that, should she die, the tissue will be destroyed or donated to research. Needless to say, these options are not the only possible ones, nor are they likely to be acceptable to all patients. This is especially true when the patient herself is legally and/or mentally incapable of consent. There is, unfortunately, no American case law that directly governs the disposition of gametes after the donor's death. Several cases involving stored sperm have considered the wishes expressed by the deceased donor during the course of his life [96–98]. For example, in *Hecht v. Superior Court*, the California Court of Appeal decided a dispute between the decedent's adult children and his surviving girlfriend over the ownership of the decedent's sperm. The court held for the girlfriend because the decedent's will, along with other actions he took during his lifetime, clearly expressed the desire that the frozen sperm pass to his girlfriend. The *Hecht* court ruled that "'the seed of life . . .[is] tied to the fundamental liberty of a human being to conceive or not to conceive.' . . . [T]he fate of the sperm *must be decided by the person from whom it is drawn.* Therefore, the sole issue becomes that of intent."

This and other cases provide little guidance here because minor children are often incapable of expressing or even forming intent as to the future use of their gametes. Very young children simply do not (and cannot) know whether or not they would want children, let alone whether they wish to have post-mortem children. This inability to express any intent is especially acute in young female patients. As we have discussed,

male patients are not candidates for gamete storage until the age of puberty. At that time, while they may not be able to fully appreciate the full meaning of fatherhood, at least they are able to express *some* preference about having children. Female patients, on the other hand, are candidates for gamete preservation at any time from birth on. Even newborn girls could theoretically be candidates for ovarian tissue removal and preservation. It is impossible to decide the disposition of tissue based on the intent of children too young to form or express an intent about childbearing. A different way of determining the disposition of the gametes must therefore be found.

There are three basic ways in which parents may wish to dispose of the ovarian tissue of a deceased daughter: it can be destroyed, donated for research,[13] or kept by relatives [14] for the purpose of having the decedent's child. It seems to us that either of the first two options is not problematic from the viewpoint of law or ethics. If the parents decide to destroy the tissue, it is really no different than deciding to bury their child's body without preserving any of her tissue – a decision countless parents make every day. Similarly, if the parents decide to donate the tissue to research, it is no different than deciding to donate their child's body or organs for research – again, a decision that many parents currently make.

The third option, on the other hand, raises serious concerns. Although no American court has directly addressed the question of disposition of a decedent's genetic material absent clear expression of the decedent's intent, two French courts have done so. In *Mme. O. c. CECOS* [99], the wife's eggs were fertilized with her husband's sperm and stored. The husband died prior to implantation of the embryos and the wife requested that the embryos be implanted after his death. The consent form that the husband and wife signed prior to storing the embryos was silent on the question of disposition in cases of death or divorce. The High Court at Rennes, France, held that, absent proof that the husband intended his wife to be sole decision-maker with respect to the future of the embryos, the wife had no authority to unilaterally decide on implantation, whether pre- or post-death. The case of *Mme. P. c. La Grave Hôpital* [100] was similar to *Mme. O.*, except for the fact that the consent form signed by the husband and wife explicitly stated that consent of both parties is necessary for implantation. After the husband's death, the court upheld the agreement even though the husband's consent was no longer obtainable, thus declining to permit Mme. P. to proceed with implantation. As in *Hecht*, both French cases held that the intent of the progenitor is of paramount importance and is to be honored. Where the donor expressed no clear intent to become a parent, however, the courts will not infer it, even if the donor is deceased.

There is heated academic debate on the proper disposition of a decedent's genetic material. Although the debate focuses on the genetic materials that were stored by adult individuals (since childhood storage is a very new possibility), much of the logic can be applied to the problem of the disposition of stored genetic material of minors. For

---

[13] Tissue cannot be donated for transplantation with cancer patients because the risk of cancer re-seeding is too high [83].

[14] "Relatives" here is broadly defined to include blood relatives, relatives by marriage, and significant others who may not have been married to the decedent, but maintained a committed sexual relationship.

instance, John Robertson argues that "directions for *or against* posthumous reproduction deserve much less respect than decisions about reproduction when one is alive," thus concluding that the surviving relatives ought to control the disposition of the decedent's genetic material [101]. On the other hand, Professor Anne Schiff argues that whenever the decedent's wishes are unknown, a presumption against using gametes for posthumous reproduction should apply [102]. Professor Schiff concludes that "[r]espect for a person's autonomy requires that an individual's body or body parts not be utilized without that individual's prior consent," at least when not "justified by the compelling societal interest that exists . . . in saving lives and alleviating suffering."

Given the academic debate, we cannot predict how courts and legislatures would approach the issue of gamete ownership when the late progenitor has failed to express any wishes as to the disposition of the gametes. It seems possible that given the general reluctance of the courts both in this country and abroad to approve of non-consented reproduction, the default position may well be that the surviving family members will be prevented from using the deceased relative's gametes. On the other hand, given that the Uniform Anatomical Gift Act (the "UAGA") reposes the authority to donate the organs with the surviving relatives (unless the decedent expressed wishes to the contrary) [103], and permits the family to designate the recipient of those organs, the courts may permit family members to do as they desire.

What is clear is that the courts are honoring the written agreements made when the genetic material was stored. Thus, it is incumbent upon any clinic participating in the oncofertility program to develop a consent form where post-mortem options are listed and explained to the consenting parties. The list of options should be developed in consultation with the clinic's attorney in light of the laws of the jurisdiction and in consultation with a bioethicist. To the extent possible, the views of the minor should also be solicited as they may inform (though they may not be determinative) any decision on the fate of the stored gametes should the minor die.

Can Research on the Tissue Be Conducted and if So, What Steps Must the Researchers Take?

Finally, we wish to consider the issue of research on the tissue that was excised to preserve the patient's fertility. The Oncofertility Consortium at Northwestern University asks the patient who has decided to freeze her ovarian tissue to donate 20% of that tissue for research. Participation in the program, however, is not predicated on consent and women retain the option to refuse to donate. Thus far, all women have consented to donate a portion of their ovaries to research. Nonetheless, there is always a possibility that some women may feel such pressure to donate that their consent is not truly voluntary. What are the conditions that would ensure that any consent to research on the excised tissues has been freely given?

As previously discussed, competent adult patients are free to dispose of their tissues as they will, including donating parts of it for medical research. Thus, overall, the guidelines with respect to obtaining tissue for research would parallel general guidelines on seeking

patient's directives on tissue disposition. There must, however, be additional precautions to ensure that the decision made by the patient is truly free from any coercive effects. In our view, the guidelines of the UAGA are a good starting point in designing procedures meant to eliminate coercion.

Under the UAGA, a physician who attends the death of a donor is not permitted to be involved in the organ harvesting or transplantation because this may create a conflict of interest for the physician [103]. Though in the case of donating ovarian tissue the donor is not dead, a similar conflict may exist. The treating physician may have a conflict (or a perceived conflict) between focusing on treatment (whether oncological or fertility) and focusing on research. The physician may (at least theoretically) be swayed in his or her efforts depending on the patient's decision to donate or not donate parts of her tissue. Thus, taking the lead from the UAGA guidelines, it would be best if the donation were sought and obtained by personnel not involved with the treatment of the patient. Ideally, the treating physician should not know whether the patient chose to donate part of her tissue, lest his or her reaction to the decision affect the treatment provided to the patient.

Furthermore, in seeking the patient's consent to donation, physicians should disclose any financial interest they may have in the project. As the California Supreme Court noted in *Moore v. Regents of University of California*, in order for the consent to be truly free, a patient must rest assured that the treating physician is not improperly "influenced by a profit motive." As the court observed:

> A physician who adds his own research interests to this balance may be tempted to order a scientifically useful procedure or test that offers marginal, or no, benefits to the patient. The possibility that an interest extraneous to the patient's health has affected the physician's judgment is something that a reasonable patient would want to know in deciding whether to consent to a proposed course of treatment. It is material to the patient's decision and, thus, a prerequisite to informed consent [104].

It may be argued that in *Moore*, the court was concerned with procedures being done to the patient in vivo in order to bolster the research being done in vitro and that the same concerns do not apply to oncofertility research that would involve tissue already voluntarily excised from the patient. Thus, the argument goes, the donation to research would not subject the patient to any additional risks, the researcher would not have a conflict of interest, and therefore the patient would not need to take that conflict into consideration in deciding whether to consent to research. While the observation that in vitro research does not necessarily involve any risk to the patient or conflict of interest for the researcher is correct, this argument does not apply to oncofertility research. For one thing, oncofertility patients, unlike the patient in *Moore*, do not have diseased organs, for which they have little use, excised. Rather, oncofertility patients preserve their tissues precisely because they expect to use them in the future. Thus, they may be disinclined to surrender any part of that tissue for fear that such surrender would diminish their chances of having a child. Furthermore, the conflict of interest may still be present. The tissues are excised in order to preserve fertility and the ability to have children in the future;

therefore, the primary concern of physicians should be helping their patients conceive when and if they desire to do so. Pursuing their own research interests may conflict with physicians' responsibility to treat their patients' infertility.

For the reasons outlined, it is critical that oncofertility programs adopt strong guidelines that ensure that patients can make truly informed and uncoerced decisions about whether or not to donate their tissues to research.

Are There Additional Concerns?

This chapter is by no means an exhaustive treatise on the legal, moral, and ethical questions that surround the field of oncofertility. Questions of financing, religious objections, and access must be considered by both those who set up oncofertility programs and those who decide on public policy concerning them. The Oncofertility Consortium continues to examine these issues and we expect that future scholarship by other members of the Consortium will expand the analysis we provide here.

Conclusion

The emerging field of oncofertility holds out new hope and possibilities for individuals whose fertility may be compromised by disease of reproductive organs or medical treatment. With further advances in the science, the patients will retain the ability to have children and to exercise their freedom to make reproductive decisions. However, as science develops, the scientists and physicians also acquire responsibilities to make sure that these advances are not used in an unethical or illegal manner. This chapter attempts to outline several difficult problems that oncofertility practitioners, patients, and patients' families are likely to face. We hope that our analysis will stimulate needed discussion in the laboratories, clinics, and at the bedside, and that through this ongoing dialogue, strong ethical and legal guidelines will emerge.

Acknowledgments This research was supported by the Oncofertility Consortium NIH 8UL1DE019587, 5RL1HD058296. This chapter is an abridged version of a law review article that previously appeared in 49 SANTA CLARA L. Rev. 673 (2009).

References

1. National Cancer Institute. The Nation's investment in cancer research: a plan and budget for FY2009. United States: 2008. http://plan.cancer.gov/pdf/nci_2009_plan.pdf. Accessed September 2, 2009.
2. National Cancer Institute. SEER cancer statistics review 1975–2005. United States: 2008. http://seer.cancer.gov/csr/1975_2005/results_merged/sect_01_overview.pdf. September 2, 2009.
3. Loscalzo MJ, Clark KL. The psychological context of cancer-related infertility. In:Woodruff TK, Snyder KA, Eds. Oncofertility: fertility preservation for cancer survivors. New York: Springer; 2007:180–90.
4. Roberts DE. Killing the black body: race, reproduction and the meaning of liberty. New York: Vintage Books; 1997.
5. Robertson JA. Children of choice: freedom and the new reproductive technologies. Princeton: Princeton University Press; 1994.
6. *Skinner v. State of Oklahoma, ex. rel. Williamson,* 316 US 535 (1942).
7. *Griswold v Connecticut,* 381 US 479 (1965).
8. *Eisenstadt v Baird,* 405 US 438 (1972).
9. *Ohio v Akron Center for Reproductive Health et al.,* 497 US 502 (1990).

10. *Universal Declaration of Human Rights*. G.A. Res. 217A(III), art. 16(1), U.N. GAOR, 3d Sess., U.N. Doc. A/810 (Dec. 10, 1948).
11. *International Covenant on Civil and Political Rights*. art. 23(2), 999 U.N.T.S. 179. (Dec. 16, 1966).
12. *European Convention for the Protection of Human Rights and Fundamental Freedoms*. art. 12, 213 U.N.T.S. 222. (Nov. 4, 1950).
13. *The Cairo Declaration on Human Rights in Islam*, August 5, 1990, World Conference on Human Rights, U.N. DOC. A/CONF.157/PC/62/Add.18 (June 9, 1993)
14. *Nahmani v Nahmani*, CFH 2401/95, (1996) IsrSC 50(4) 661 (opinion of Dorner, J.). http://elyon1.court.gov.il/Files_ENG/95/010/024/z01/95024010.z01.pdf.
15. *720 ILL. COMP. STAT. ANN.* 510/6 (West 2003).
16. *IA. REV. STAT. ANN.* § 9:121 (2008)
17. *23 PA. CONS. STAT. ANN.* § 5102 (West 2000 & Supp. 2008)
18. *N.H. REV. STAT. ANN.* § 168-B:13.
19. *18 PA. CONS. STAT. ANN.* § 3213(e).
20. *Fertility Clinic Success Rate and Certification Act of 1992*, 42 U.S.C. § 263a-1 (2006).
21. Arons J. Future Choices: Assisted Reproductive Technologies and the Law. *Center for American Progress*; 2007. http://www.americanprogress.org/issues/2007/12/pdf/future_choices_section1.pdf. Accessed September 2, 2009.
22. *Davis v. Davis*, 842 S.W.2d 588, 600 (Tenn. 1992).
23. *J.B. v M.B.*, 783 A.2d 707, 715–16 (NJ, 2001).
24. *Kass v. Kass*, 696 N.E.2d 174, 180 (NY, 1998).
25. *In re Baby M*, 537 A.2d 1227, 1246–47 (NJ, 1988).
26. Callahan JC. Reproduction, ethics and the law: feminist perpsectives. Bloomington: Indiana University Press; 1995.
27. Raymond JG. Women as wombs: reproductive technologies and the battle over women's freedom. New York: HarperCollins; 1993.
28. Rothman BK. Recreating motherhood: ideology and technology in a partriarchal society. New York: W.W. Norton & Co; 1989.
29. *Casey*, 505 U.S. at 899.
30. *CAL. WELF. & INST. CODE*. § 14503.
31. *Carey v Population Servs, Int'l*, 431 U.S. 678 (1977).
32. *Winters v Miller*, 446 F. 2d 65, 68 (2nd Cir. 1971).
33. Dolin G. A Health or an Executioner? The Proper Role of a Psychiatrist in a Criminal Justice System. J Law Health. 2002; 17:169–216.
34. *Schloendorff v Soc'y of N.Y. Hospital*, 105 N.E. 92, 93 (1914).
35. *VA. CODE ANN.* § 54.1-2974.
36. *GA. CODE ANN.* § 31-20–2.
37. *In re Hofbauer*, 393 N.E.2d 1009, 1013 (N.Y. 1979).
38. President's Comm'n for the Study of Ethical Problems in Med. & Biomed. & Behavioral Research. *Deciding to Forego Life-Sustaining Treatment: A report on the Ethical, Medical, and Legal Issues in Treatment Decisions*; 1983.
39. US Conference of Catholic Bishops. *Ethical and Religious Directives for Catholic Health Care Services*. 4th edn; 2001. http://www.usccb.org/bishops/directives.shtml. Accessed September 2, 2009.
40. *Troxel v Granville*, 530 U.S. 57 (2000).
41. *Wisconsin v Yoder*, 406 U.S. 205 (1972)
42. *Pierce v Soc'y of Sisters*, 268 U.S. 510 (1925)
43. *Meyer v Nebraska*, 262 U.S. 390 (1923)
44. *In re Eric B.*, 235 Cal. Rptr. 22, 27 (Ct. App. 1987)
45. *Newmark v Williams*, 588 A.2d 1108, 1117 (Del. 1990)
46. *In re Willmann*, 493 N.E.2d 1380, 1390 (Ohio Ct. App. 1986)
47. *Jehovah's Witnesses of Wash. v King County Hosp.*, 278 F. Supp. 488, 504 (W.D. Wash. 1967)

48. *In re McCauley*, 565 N.E.2d 411, 414 (Mass. 1991)
49. *In re Cabrera*, 552 A.2d 1114, 1119 (Pa. Super. Ct. 1989)
50. World Medical Association. Ethical Principles For Medical Research Involving Human Subjects. 1964. http://www.wma.net/e/policy/pdf/17c.pdf. Accessed September 2, 2009.
51. Ford KK. "First, Do No Harm" – The Fiction of Legal Parental Consent to Genital-Normalizing Surgery on Intersexed Infants. Yale Law Policy Rev. 2001; 19:469–88.
52. *Bonner v. Moran*, 126 F.2d 121, 123 (D.C. Cir. 1941).
53. Society for Adolescent Medicine. Confidential Healthcare for Adolescents: Position Paper of the Society for Adolescent Medicine. J Adolesc Health. 1997; 21:408–15.
54. American Academy of Pediatrics Committee on Bioethics. Informed Consent, parental permission, and assent in pediatric practice. Pediatrics. 1995; 95:314–7.
55. Kaufman MW, et al. Neonatal circumcision: benefits, risks, and family teaching. Am J Matern Child Nurs. 2001; 26:197–201.
56. Miller GP. Circumcision: cultural-legal analysis. Va J Soc Policy Law. 2002; 9:497–585.
57. Liptak A. Opponents of circumcision use the legal system and legislatures to combat it. NY Times. 2003 January 23:A14.
58. American Academy of Pediatrics. Circumcision policy statement. Pediatrics. 2003; 103:686–93.
59. *In re Marriage of Boldt*, 176 P.3d 388, 393 (Or. 2008).
60. *State v Baxter*, 141 P.3d 92 (Wash. Ct. App. 2006).
61. *Sweet v. Sisters of Providence*, 895 P.2d 484 (Alaska 1995).
62. *Wilson v Lockwood*, 711 S.W.2d 545 (Mo. Ct. App. 1986).
63. *Flatt v Kantak*, 687 N.W.2d 208 (N.D. 2004).
64. World Health Organization. Female Genital Mutilation. http://www.who.int/topics/female_genital_mutilation/en/. Accessed December 21, 2008.
65. *People v Sanchez*, 800 N.E.2d 455, 462 (Ill. App. Ct. 2003).
66. Kipnis K, Diamond M. Pediatric ethics and the surgical assignment of sex. J Clin Ethics. 1998; 9:398–410.
67. Beh HG, DiamondM. An emerging ethical and medical dilemma: should physicians perform
sex assignment surgery on infants with ambiguous genitalia? Mich. J Gender Law. 2000; 7:1–63.
68. American Academy of Pediatrics. Timing of elective surgery on the genitalia of male children with particular reference to the risks, benefits, and psychological effects of surgery and anesthesia. Pediatrics. 1996; 97:590–4.
69. *In re A.W.*, 637 P.2d 366, 367–68 (Colo. 1981).
70. Boozang KM. CAM for kids. Houston J Health Law Policy. 2001; 1:109–32.
71. Muckle C. Giving a voice to intersex individuals through hospital ethics committees. Wis Law Rev. 2006; 3:987–1023.
72. *Mich. Protection & Advocacy Serv. v Kirkendall*, 841 F. Supp. 796, 801 (E.D.Mich. 1993).
73. *Wentzel v Montgomery General Hosp., Inc*., 447 A.2d 1244, 1254 (Md. 1982).
74. *In re Terwilliger*, 450 A.2d 1376, 1382 (Pa. Super. Ct. 1982).
75. *In re Hayes*, 608 P.2d 635, 640 (Wash. 1980).

76. *In re Truesdell*, 304 S.E.2d 793, 806 (N.C. Ct. App. 1983).
77. *In re Marriage of Boldt*, 176 P.3d 388, 394 (Or. 2008).
78. *In re E.G.*, 549 N.E.2d 322 (Ill. 1990).
79. *Cardwell v Bechtol*, 724 S.W.2d 739, 748 (Tenn. 1987).
80. Markon J. Fight over a child's care ends in compromise; Va. Judge's order could have forced teen to get chemotherapy. Washington Post. 2006 August 17:A1.
81. Lass A. The fertility potential of women with a single ovary. Hum Reprod Update. 1999; 5:546–50.
82. Lee D. Ovarian tissue cryopreservation and transplantation: banking reproductive potential for the future. In: Woodruff TK, Snyder KA, Eds. Oncofertility: fertility preservation for cancer survivors. New York: Springer; 2007:110–29.
83. Sonmezer M, Oktay K. Fertility preservation in female patients. Hum Reprod Update. 2004; 10:251–66.
84. Demeestere I, et al. Fertility preservation: successful transplantation of cryopreserved ovarian tissue in a young patient previously treated for hodgkin's disease. Oncologist. 2007; 12:1437–42.
85. Donnez J, et al. Livebirth after orthotopic transplantation of cryopreserved ovarian tissue. Lancet. 2004; 364:1405–10.
86. Meirow D, et al. Pregnancy after transplantation of cryopreserved ovarian tissue in a patient with ovarian failure after chemotherapy. N Engl J Med. 2005; 353:318–21.
87. Silber SJ, et al. Ovarian transplantation between monozygotic twins discordant for premature ovarian failure. N Engl J Med. 2005; 353:58–63.
88. American Medical Association. Policy Compendium 87 E-2.20 (1997).
89. Delmonico FL, Harmon WE. The use of a minor as a live kidney donor. Am J Transplant. 2002; 2:333–36.
90. *Strunk v Strunk*, 445 S.W.2d 145, 146 (Ky. 1969).
91. *Hart v Brown*, 289 A.2d 386 (Conn. Super. Ct. 1972).
92. *Little v Little*, 576 S.W.2d 493, 499 (Tex. App. 1979).
93. *Curran v Bosze*, 566 N.E.2d 1319 (Ill. 1990).
94. *In re Richardson*, 284 So. 2d 185 (La. Ct. App. 1973).
95. American Medical Association. CEJA Rep. 3-I-93: The Use of Minors as Organ and Tissue Donors (1993).
96. *Hecht v Superior Court*, 20 Cal. Rptr. 2d 275 (Ct. App. 1993).
97. *Estate of Kievernagel*, 166 Cal. App. 4th 1024 (Ct. App. 2008).
98. *Kurchner v State Farm Fire & Cas. Co.*, 858 So. 2d 1220, 1221 (Fla. Dist. Ct. App. 2003).
99. Tribunal de grande instance [T.G.I. ordinary court of original jurisdiction] Rennes, June 30, 1993, J.C.P. 1994, II, 22250, 169, note Neirinck (Fr.).
100. Cour d'appel [CA regional court of appeal] Toulouse, Apr. 18, 1994, J.C.P. 1995, II, 224072, 301, note Neirinck (Fr.).
101. Robertson JA. Posthumous reproduction. Indiana Law J. 1994; 69:1027–65.
102. Schiff AR. Arising from the dead: challenges of posthumous procreation. NC Law Rev. 1997; 75:901–65.
103. UNIF Anatomical Gift Act
104. *Moore v Regents of Univ. of Cal.*, 792 P.2d 479, 484 (Cal. 1990).