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Therapeutic Reproduction and Human Dignity

Richard F. Storrow*

Abstract. The article explores current controversies in therapeutic reproduction through the lens of two contemporary novels as well as with the aid of ethics pronouncements made by the American Society for Reproductive Medicine and the European Society for Human Reproduction and Embryology.

Keywords: literature, reproduction, cloning, organ banking

INTRODUCTION

Bioethicists have long embraced literature as a valuable tool for analysis.¹ Their interest in literary narratives is unsurprising. Advances in biotechnology present questions of who we are as individuals and who we are as a species,² questions to which the humanities have offered responses for millennia.³ As part of a larger “narrative practice of bioethics,” the study of fiction can be transformative in addressing not only existing bioethical dilemmas but also ones that yet remain in the realm of speculation.⁴

A body of literature is now emerging in response to specific controversies in bioethics, including those triggered by the intersection of reproduction-assisting technologies and the crisis in human organ donation.⁵ Two recent novels in this vein wrestle with the ethics of using reproductive technology to create donors of human tissue and organs. In Jodi Picoult’s *My Sister’s Keeper*, set in the United States, Brian and Sara Fitzgerald use reproductive

technology to conceive a child to serve as a donor for their leukemia-stricken daughter Kate.⁶ For years Anna submits to increasingly aggressive medical interventions in order to donate tissues for Kate's care. When she is asked as a teenager to donate a kidney to Kate, Anna responds by suing for medical emancipation from her parents. The backdrop of Kazuo Ishiguro's *Never Let Me Go* is a governmental program that pursues cures for cancer and heart disease with organs extracted from a stable of human clones.⁷ The novel is the story of Kathy H., a clone who relates what it was like to grow up in an institution established under this program and how she and a fellow inmate eventually confronted an official whose efforts to make the program more humane had failed.

At first blush, *My Sister's Keeper* and *Never Let Me Go* appear to have little in common. *My Sister's Keeper* examines a technology that is currently available, while *Never Let Me Go* speculates about a use to which technology might be put in the future. *My Sister's Keeper* is the story of an individual family's struggle to save their dying daughter. *Never Let Me Go* is the story of an entire society that, in the name of public health, requires one class of people to surrender their lives for the benefit of others. Finally, the highest accolade for *My Sister's Keeper*, as long on melodrama as Picoult's other best-sellers, has been its great popularity. By contrast, *Never Let Me Go* made the short list for the Mann-Booker prize in 2005 and has otherwise been on several "best books" lists.

Despite their dissimilarities, the Library of Congress classifies both *My Sister's Keeper* and *Never Let Me Go* as its only works of fiction having to do with human organ donors. This is significant, for it is the donors' perspectives in these novels that raise important questions about the lengths to which families and society should go to heal those stricken by disease. Reading the novels together reveals remarkable parallels between the deference paid to parents in matters of reproduction and child rearing and to government in its pursuit of public health aims. Such deference has the effect of obscuring if not necessarily illegitimizing what could be more critically searching evaluations of parental or governmental attempts to instrumentalize human reproduction.

Beyond these more general themes, both *My Sister's Keeper* and *Never Let Me Go* ask us to reconsider debates about the specific bioethical questions they raise. These debates have taken very different paths. Policymakers and ethicists tend to describe a couple's choice to conceive and raise a "savior sibling" as an act of love and responsible parenting but have reviled reproductive cloning as

an affront to human dignity, both because of the repugnance it engenders and because human clones lack a connection to two genetic parents. Some of these same policymakers have hailed cloning embryos for the purpose of stem cell research and therapy as positive and humanitarian. Britain has embraced both of these positions by most recently enacting a law that permits the creation of savior siblings under certain conditions.⁸ In a former parliamentary session, Britain outlawed human reproductive cloning but permitted cloning human embryos for stem cell research.⁹

My Sister's Keeper and *Never Let Me Go* successfully problematize the bright lines drawn between ethically permissible and ethically impermissible uses of reproductive technology. First, they call into question dichotomies between reproduction and therapy and between family and state that have permitted easy distinction between what is good and what is bad about reproductive technology. These dichotomies project parents as proper consumers of existing technology that helps them achieve their reproductive aims and government as a proper promoter of technology aimed at curing dreaded diseases. The novels suggest that it is misguided to conceive of parental and governmental competencies as inhabiting wholly separate spheres. They caution that what we fail to appreciate in holding to these dichotomies is that reproduction and therapy are not distinct but that both parents and the state in their supposedly separate spheres are capable of harnessing reproductive power to create children for the therapy of others.

Second, the novels reveal the concept of human dignity to be insufficiently definite to be used for accurate line drawing in these ethical controversies. Certainly if human clones have no dignity because of their biological origins, as the stance against human reproductive cloning holds, their creation for humanitarian therapeutic ends is difficult to classify as an antihumanitarian crime. On the other hand, if the biological origins of human clones do not predetermine their potential for personhood, as *Never Let Me Go* demonstrates, why should the law prohibit their creation? With regard to savior siblings, the appeal to dignity is similarly tenuous because it rests on slender assumptions about parental motivations and devotion as well on speculations about a donor sibling's psychology that *My Sister's Keeper* quite easily calls into doubt. By exploring the human struggle and emotions that come into play when we employ the power of human reproduction to solve difficult medical problems, Picoult and Ishiguro implore us not to be satisfied with the ease and certainty that have to date characterized ethical pronouncements in this area.

SAVIOR SIBLINGS

For many years, it has been possible to determine the health of a pregnant woman's fetus with the aid of prenatal genetic diagnosis.¹⁰ At times, parents will elect to abort a fetus they discover has severe abnormalities. With the development of tools for preimplantation genetic diagnosis (PGD), it has become possible, in combination with in vitro fertilization, to test embryos for genetic and chromosomal defects so as to avoid commencing a pregnancy that would later require termination. The same technology, in combination with human leukocyte antigen (HLA) tissue profiling, permits parents with a sick child who could benefit from donations of tissue to select an embryo that will develop into a compatible donor. Prior to the advent of PGD and HLA typing, parents with sick children were limited to testing fetuses in utero and aborting those whose tissues would be unsuitable for therapy,¹¹ a practice that generated consternation among some commentators.¹² Since PGD and HLA are effective, it is felt ethically preferable to proceed in that manner, the burden on embryos and parents being less acute.

Parents planning to create a savior sibling intend that the child will donate umbilical cord blood, regenerative tissue such as bone marrow, and, potentially, a nonregenerating organ to promote the health of the sick sibling.¹³ The savior sibling herself may be, but is not always, medically benefited by the PGD. In the case of an inherited disease, PGD can ensure that the savior child will not have the disease. The medical benefits for the donee include not only the therapy itself but also circumventing the perennial shortage of human tissue available for transplant and avoiding the risk that the donee's body will reject the transplant.¹⁴

Ethics Pronouncements

There is diversity of opinion on the ethics of creating savior siblings, and the analysis of the question shares some characteristics with ethics pronouncements on sex selection for social reasons. As one might expect, physicians' associations disagree about whether sex selection is ethical "when it is aimed at serving social and psychological goals not related to the prevention of disease."¹⁵ Although both the American Society for Reproductive Medicine (ASRM) and the European Society for Human Reproduction and Embryology (ESHRE) believe sex selection for the purposes of disease prevention is

ethical,¹⁶ ASRM rejects using PGD for sex selection for nonmedical reasons,¹⁷ and constituents of ESHRE's Ethics Task Force have expressed two positions—(1) PGD and sex selection for nonmedical reasons are always unacceptable and (2) PGD and sex selection for nonmedical reasons are acceptable to “balance” the genders of the children in a family.¹⁸ Under the latter view, it would be unethical to select the gender of a first child. As long as sperm-sorting techniques are safe, ASRM does approve of preconception sex selection for family balancing or for first children because it imposes fewer burdens on embryos and parents.¹⁹

The rationales offered for labeling sex selection for nonmedical purposes as ethical or unethical are many and include fears about sex bias and societal gender imbalances.²⁰ More relevant to the present discussion are the concerns that nonmedical sex selection trivializes reproduction, instrumentalizes offspring, and presents too great a risk of psychological and emotional harm to the children.²¹ In essence, these are fears that, in selecting the genetic profiles of their children, parents take the wrong approach to reproduction. The belief is that the expectations parents will generate in wielding such control over the reproductive process will have negative psychological and emotional ramifications for their children.

The same concerns underlie discussion of the ethics of creating savior siblings.²² ESHRE articulates both ethical and legal justifications in favor of their creation. ESHRE's legal opinion draws support from the presumption that parents will act in the best interests of their children. ESHRE believes that the presumption encompasses the determination of fully informed and counseled parents to impose a detriment upon their child for the benefit of his sibling, at least where they judge that the “risks are outweighed by the benefits for the receiving sibling.”²³ From this reasoning, ESHRE fashions a “postnatal test” for savior siblings: “If the parents have the authority to ‘volunteer’ an existing child as a bone marrow donor for a sibling, it is also acceptable that they create a child as a bone marrow donor for a sibling.”²⁴ The condition embodied in the postnatal test reflects the fact that the law sets a higher standard for parental decision making when the medical procedure is of no direct medical benefit to the donor child.²⁵ ESHRE and commentators have suggested that this higher standard can be met through the psychological benefits the donor receives from helping the sick sibling, benefits that range from contributing to the family's stability and survival to the boost in self-esteem gained from having a power to heal that others lack.²⁶ ESHRE's second legal argument in support

of the creation of savior siblings is that a court may substitute its judgment for that of the unconceived donor in the same way it does when considering whether medical procedures should be performed upon persons too incapacitated to give informed consent.²⁷ In the context of savior siblings, ESHRE anticipates that a court will conclude that “the future sibling on whose behalf the decision to donate is made will agree with the present decision when he/she becomes autonomous.”²⁸ Despite its generally favorable attitude toward the creation of savior siblings, ESHRE cautions that creating a child to donate nonregenerating organs is unacceptable “in view of the risks involved for the donor child.”²⁹

As an ethical response to fears that savior siblings will not enjoy “full respect for their personal uniqueness and dignity,”³⁰ ESHRE believes using PGD for HLA matching is not instrumentalizing if obtaining tissue is not the only motive for the parents to have the child. As long as the parents intend to love and care for the donor child to the same extent as they love and care for the affected child, they can clear this “single-motive” hurdle³¹ and avert psychological and emotional harm to the donor offspring. This ethical analysis is similar to ASRM’s position that preconception gender selection is acceptable where parents are counseled against unrealistic expectations and “affirm that they will fully accept children of the opposite sex if the preconception gender selection fails.”³²

Commentators on the single-motive test emphasize how extremely difficult it would be to show that parents harbor a single motive for creating a savior sibling.³³ Indeed, especially when parents undertake Herculean efforts to save their sick child, it perhaps is highly unlikely that they will treat their carefully chosen donor child with any less devotion,³⁴ especially if the donations successfully treat the sick child.³⁵ In that case, the donor may actually receive an emotional boost from having been of such great assistance.³⁶ The thrust of these perspectives is that without red flags to warn us that parents will abuse, neglect, or abandon their donor children, we lack justification for assuming anything other than that a parental project to create a child to save another falls well within the sphere of deference parents have traditionally enjoyed.³⁷

Of course, not every ethical analysis proceeds in the direction of general permissiveness. Convened by former President Bush in 2001, the President’s Council on Bioethics took a very firm stance against sex selection for nonmedical reasons and expressed a number of concerns about the creation of savior siblings. The Council was particularly concerned that when

technology removes the “genetic lottery” from human reproduction, parental expectations become fixed in ways that deprive the resulting children of an “open future.”³⁸ In the case of nonmedical sex selection, the Council adopted reasoning from its earlier work opposing human reproductive cloning and stated: “[W]e should be reluctant to see ourselves as people who may appropriately dictate such a crucial part of the identity of our child [lest we turn human reproduction] into a form of manufacture and open the door to a new eugenics.”³⁹ The Council disagreed that counseling and a parental affirmation that a child of the undesired gender will be fully accepted pull the poison from sex selection.⁴⁰ Similarly, the President’s Council did not dispute that savior siblings are probably loved by their parents but nonetheless queried whether assigning the role of savior to a child as a condition for its existence is an appropriate exercise of human reproductive potential.⁴¹ In essence, the President’s Council viewed the creation of savior siblings as a genetic trait selection technology that goes beyond therapy.⁴² Unlike ESHRE and ASRM, then, the President’s Council believed these technologies to threaten important understandings of human reproduction and even of human dignity.

My Sister’s Keeper

Running through much of the ethical analysis on savior siblings is not only the idea that parents should be permitted to resort to desperate measures to save the life of their child but that within individual families there are special moral bonds that require extraordinary sacrifices where there is “a substantial family need.”⁴³ In addition, ethics commentators remain committed to the idea that parents intend to love and care for their donor children or can be educated to do so.⁴⁴ Jodi Picoult’s *My Sister’s Keeper* weaves a story that implicates and problematizes these perspectives. Even more significantly, her tale compels us to consider what ramifications broad deference to families facing medical crises carries for governmental initiatives to address serious public health problems.

In *My Sister’s Keeper*, Anna Fitzgerald is a savior sibling who has donated cord blood, white blood cells, and bone marrow to her leukemia-stricken sister Kate. When she is thirteen and her parents, Sara and Brian, ask her to give up her kidney to save her dying sister, she instead sues for medical emancipation. Since the discovery of Kate’s illness, the energies and resources of this family have gone largely to prolonging her life. Anna understands why

she was created and what is expected of her.⁴⁵ But after years of invasive and painful medical treatments of no benefit to herself, Anna wants to forge an identity that is not defined in terms of treating her sister's illness.

There is no question that an important part of what drives Picoult's story is its melodrama and overwrought metaphors.⁴⁶ Kate's continual relapses ensure that a family crisis develops every few pages. An extended metaphor finds the firefighter husband describing his family as a house fire out of control⁴⁷ and the neglected older son, Jesse, turning to arson. But in addition to these trappings of popular fiction, Picoult skillfully employs a multiple first-person, present-tense narration that enhances the immediacy of the story and thus the reader's sense of its veracity. This structure also effectively exposes the rarely glimpsed complexity of family dynamics and in this way helps put meat on the bones of the pared-down ethical analysis discussed above. Central to this project is the character of the guardian ad litem, Julia, who must mediate between the family and the legal establishment. Julia's greatest contribution to our ethical understanding of creating savior siblings is the reminder, completely absent from the ethical pronouncements on this issue, that families who create savior siblings remain in crisis long after the savior's birth. The fraught Fitzgeralds certainly pass the anemic "one-motive" test, but barely. In particular, Sara fails at nearly every opportunity to describe or relate to Anna in any way other than what she means for the life and health of her sister.⁴⁸ In this way, her love and care for Anna seem precariously contingent. Her rage at Anna's assertion of autonomy,⁴⁹ however, does not signal bad mothering; it is symptomatic of the sick child's overwhelming influence on everything that takes place in the life of this family. Brian and Sara simply have no resources left with which to attend to their other children as autonomous individuals.

Picoult's tale not only problematizes pithy ethics pronouncements; it also leads us to consider what insulating families from interference, when they try to resolve difficult health issues, suggests about the lengths government might go to do the same. If we feel it is justifiable for a family to call upon or create its members to make extraordinary sacrifices in order to preserve the family's integrity and interests, we have strong analogical support for government to address a serious public health crisis through extraordinary measures, including, perhaps, the harnessing of reproductive potential.⁵⁰

Harnessing reproductive potential to address a public health crisis is admittedly more concerning than, for example, requiring inoculations against rampant disease. Although in the past the justification for inoculations has been

raised in support of a government program to sterilize “mental defectives,”⁵¹ more recently concern about the human rights trodden upon by government’s manipulation of procreation has succeeded in undermining its authority to pursue its aims by those means.⁵² In *Never Let Me Go*, the subject of the next section, Kazuo Ishiguro imagines a world in which the products of cloning technology are not considered human and thus, like other chattels, are appropriate targets for instrumentalist regulation. This sounds like the premise of a dystopic reflection on the abuse of power, but if we take a close look at the ethical pronouncements responding to human reproductive cloning and cloning for stem cell research we find abundant language that tends inexorably in the direction of the world that Ishiguro imagines in the Britain of just yesterday.

HUMAN CLONING FOR ORGAN BANKING

In contrast to the differing opinions about the ethics of nonmedical sex selection and savior siblings, international disapproval of human reproductive cloning has surged, with statutory bans currently ranging from individual states within the United States all the way up to the United Nations.⁵³ What most distinguishes discussions of the ethics of human reproductive cloning at the legislative level from the discussion of savior siblings by ethics bodies is the absence of any sense that families should receive deference in choosing to produce cloned offspring. Instead, the most powerful engine driving the disapproval of human reproductive cloning is that it poses too great a threat to human dignity.⁵⁴ This concern takes several forms, from the fear that clones would be mere genetic copies lacking in individuality to the fear that rogue physicians will clone individuals without proper permission.⁵⁵ In addition, the humanity of clones themselves might be easy to discount, leading to all sorts of harm, including such “unrealistic” and “esoteric” applications as the creation of human organ factories.⁵⁶

Ethics Pronouncements

Some of the ethics bodies described in the section on savior siblings have issued pronouncements about human reproductive cloning. As ESHRE does in its opinion on sex selection for family balancing, ASRM outlines the pros

and cons of human reproductive cloning and ultimately concludes that it is an unethical practice in the absence of greater assurances of its safety and a more complete airing of the ethical concerns it raises.⁵⁷ Arguments in favor of cloning take the position that it is a suitable reproductive option for the infertile.⁵⁸ Arguments against posit that human cloning deprives reproduction of its mystery and sanctity and devalues the genetic distinctiveness of each individual.⁵⁹ These arguments are echoes of the view that nonmedical sex selection and the creation of savior siblings trivialize and instrumentalize reproduction. Another common fear is that parents and society would harbor undue expectations about their cloned children that would cause them to suffer psychological and emotional harm.⁶⁰

Like the legislative bodies mentioned above, the President's Council on Bioethics believed human reproductive cloning threatens human dignity. It saw dignity in reproduction as dependent upon a certain way of coming into existence:

[C]ertain applications of embryo manipulation and assisted reproductive techniques could deny to children born with their aid a full and equal share in our common human origins, for instance by denying them the natural connection to two human genetic parents or by giving them a fetal or embryonic progenitor. We believe that such departures and inequities in human origins should not be inflicted on any child. We therefore recommend that, in an effort to secure for children born with the help of ARTs the same rights and human attachments naturally available to children conceived *in vivo*, Congress should: Prohibit attempts to conceive a child by any means other than the union of egg and sperm.⁶¹

This statement might reasonably be interpreted as similar in substance to the ASRM's enumeration of arguments against cloning. It might mean, for example, that it would be undignified to permit forms of reproduction that expose offspring to psychologically harmful exclusion or discrimination. It might also mean that it is an indignity to trivialize human procreation with a form of reproduction that lacks a genetic lottery. To do so might be said to instrumentalize reproduction by commodifying offspring.

Beyond these consistencies with the ASRM's concerns, however, the President's Council's statement might also mean that, lacking two genetic parents, human clones simply are not fully human. If so, the message resonates with recent arguments for allowing scientists to create stem cells by means of

research cloning. Faced with opposition to this research grounded in deeply held convictions about the moral status of human embryos, scientists are now developing technological and linguistic means for alleviating these concerns. On the one hand, scientists want to explore a cloning technique for creating embryos that are incapable of implanting in a uterus and gestating to term.⁶² On the other, based on the lack of success scientists have experienced in attempting to gestate cloned primate embryos to term, scientists want to characterize cloned human embryos as unconnected with the rest of humanity:

[T]he nature of an embryo seems best understood by reference to its very special teleological trajectory. An embryo reflects an evolutionary history comprised of a unique genetic lineage through countless generations. It also reflects a developmental future to be connected to the maternal body. If our analysis is correct, then cloned human blastocysts lack this teleological trajectory. They lack predecessors in evolution. . . .⁶³

Given that cloned human embryos lack a human teleological trajectory, the authors conclude it would be a mistake to refer to them as embryos or blastocysts and instead suggest the term “clonotes.”⁶⁴ It is hoped that this change in nomenclature will better convey the idea that cloned human embryos cannot become human beings and thus will help defeat moral objections to supporting stem cell research with cloning technology.

Never Let Me Go

Recent ethical analysis of human reproductive cloning and cloning for stem cell research casts both cloned embryos and clones as not fully human. In *Never Let Me Go*, Kazuo Ishiguro makes use of these perspectives to imagine a governmental program wherein human clones are created, husbanded, and killed for the use of their vital organs in medical treatment. Through the use of the memoir form, behind which the contours of the organ banking program are gradually revealed, Ishiguro provides a sound basis for rejecting the position that human clones lack dignity.

Kathy H., the author of this memoir is a human clone approaching the point in her life when she will give up her vital organs and die. Her memoir is a reflection on the entire sweep of her life, recalled in three stages—childhood, adolescence, and adulthood. She remembers Hailsham, the boarding school where she spent her childhood, and the friends and teachers she had there. She

remembers her adolescence and her confused reaction to her emerging sexuality. She reveals how, in adulthood, she has become aware of how deliberately sheltered the students of Hailsham were from the outside world and how they were deprived of any knowledge of their function in it. She explains how, in adulthood, the illusion she and others held in adolescence that a true romantic love between two students might entitle them to a temporary reprieve from their forced donations was exposed as an unfounded rumor. Kathy never rails against the fact that she was created to fulfill a function that severely limits her circumstances and opportunities. Her memoir is thus a thoughtful and resigned look back upon her life by one who accepts that death is near.

Although the organ banking program is the backdrop of this story, as Kathy enters adulthood she, as a carer for clones who are undergoing organ removal, becomes more directly involved in its workings. What begins to be confirmed at this stage is that Hailsham was one of the “privileged estates”⁶⁵ in which human organ donors received a level of care and range of opportunities superior to those afforded clones raised in other institutions under appalling conditions. Hailsham was an experiment established by those in the political establishment who wanted the clones to be treated as humanely as possible and indeed who desired to demonstrate the clones’ humanity to the world at large. The effort ultimately fails for lack of political support. Hailsham is closed, and the director whose career was devoted to the clones’ well being retires in dejection.

Despite its gruesome premise, *Never Let Me Go* does not read as a cautionary tale or dystopia. Unlike Picoult, Ishiguro very carefully regulates the dramatic tension in this story. The idea of human cloning for organ banking is never exploited for shock value. Unlike many cloning tales, Ishiguro’s eschews power-hungry physicians, money-crazed titans of commerce, and other conventions of the genre. That the narrator’s thoughts, memories, and reflections remain squarely in the foreground makes *Never Let Me Go* not a complete stylistic departure for Ishiguro. Ishiguro has specifically described his novels prior to *The Unconsoled* as employing “a method where somebody look[s] back over his or her life in old age,”⁶⁶ and we sense that Ishiguro has returned in *Never Let Me Go* to a project conveying “the viewpoint of someone looking back and ordering his experience. . . .”⁶⁷ What distinguishes *Never Let Me Go* from *A Pale View of Hills*, *An Artist of the Floating World*, and *The Remains of the Day* is that it does not attempt as those novels do to be historically accurate. Ishiguro himself believes the historical accuracy of his

early works distracts readers from thinking deeply about “abstract themes, the emotional story.”⁶⁸ Nonetheless, *Never Let Me Go* possesses more similarities with Ishiguro’s early novels than to *The Unconsoled*, which “draws on slippages in time and place as well as the voices of memory.”⁶⁹ *Never Let Me Go* is not set “in a world that is so odd, so obviously constructed according to another set of priorities.”⁷⁰ Indeed, apart from the organ banking program itself, the atmosphere Ishiguro imagines in late 1990s Britain is entirely familiar. Further linking *Never Let Me Go* with Ishiguro’s earlier works is his storytelling through dreams, the imagination, and distances. Like Ishiguro’s other novels, *Never Let Me Go* is “pervaded by memory, the reverie of individuals trying heroically to comprehend their place in the world.”⁷¹ It is a coming of age, reaching maturity, and reflecting upon “the remains of childhood and youth,”⁷² and of loss which takes the form of reminders of the way things used to be.⁷³

Even if it is not Ishiguro’s project in *Never Let Me Go* to warn us about how relaxing our vigilance can result in governmental power running roughshod over human rights, he nonetheless skillfully forces us to confront the undeniable humanity of human clones. The narration is replete with mundane reminiscences about disagreements with friends and favorite teachers and more philosophical ones about the joys of childhood, the angst of adolescence, and devotion to loved ones through thick and thin. Most poignantly, the clones begin to wonder about their “model,” the one from whom they have received their genetic inheritance. Indeed, their curiosity “kept growing and growing over the years until it came to dominate our lives.”⁷⁴ This burning curiosity is an echo of the quest for genetic progenitors by adoptive children and children born of third-party gamete donation or third-party gestation in assisted reproduction that has become such a prominent part of the debate over the ethics of reproductive technology. It has been posited in this debate that it is a human right for everyone to have access to information about their genetic origins because this fundamental part of our ongoing quest for identity is something that defines us as human. Ishiguro punctuates this poignancy by making the clones separate from society in such a way that they begin to question their humanity. The suggestion is even made among them that they were not created from human beings who lived normal lives but from societal rejects such as convicts and prostitutes. They are not only raised in institutions that separate them from the outside world, but, when they emerge more and more into the outside world, they seem always to be on the periphery. What the outside world does not see is

that they act and do things in the same way we all do: they listen to music, they gossip, they play sports, they have arguments. They pass as humans and in the very act of passing are terrified that they will be discovered and rejected as not qualifying as human in some unarticulated but essential way.

In sum, *Never Let Me Go* is a natural outgrowth of the familiar terms underlying vehement opposition to human reproductive cloning, terms that also have found their way into arguments in favor of human cloning for stem cell research. Embracing Kathy's story forces us to conclude that human clones are every bit as human as the rest of us if only because their lives are likewise defined by love and loss and hope. If human dignity is indeed that special quality that makes us more than beasts yet less than gods,⁷⁵ then Kathy's memoir demonstrates that even those who have a genetic inheritance from a single person possess it in equal degree.

CONCLUSION

Jodi Picoult's *My Sister's Keeper* and Kazuo Ishiguro's *Never Let Me Go* effectively complicate the prevailing ethical views on creating savior siblings and human cloning that offer tidy resolution of the pressing questions emerging from the actual and potential uses of these technologies. *My Sister's Keeper* calls into question the assumptions underlying the idea that parents and families deserve great deference when they decide to create a child to save another. Whereas ethics pronouncements present the creation of a savior sibling as a way to resolve a familial crisis, *My Sister's Keeper* demonstrates how the savior's presence can actually intensify the crisis. The presentation of the donor's perspective alongside her parents', an element barely referenced in ethics reports, destabilizes pithy pronouncements about unconditional love and the ease of educating parents to exhibit equanimity when their projects do not proceed as planned. *Never Let Me Go* presents the ramifications of similar deference for a government pursuing important public health objectives. By revealing the details of the organ donation program within the story of a human clone whose life has been defined by love and loss and hope, the novel cautions us that, if human clones are ever born, any move to classify them as lacking essential elements of personhood will be dishonest.

While Ishiguro treats a technology all agree is not yet feasible, Picoult propels her story forward with an account of a technology used on a daily basis

in the infertility industry. Whereas Picoult's story unfolds within the familiar confines of a suburban family struggling with everyday disappointments and frustrations, Ishiguro's takes place in an eerily unfamiliar institution created for raising compliant human organ donors. Upon closer examination, any significant dissimilarity between these two novels dissolves in their tackling of the profound question of whether it is morally permissible to create human beings for the purpose of treating the illnesses of others.

In addressing this question, both novels counsel against ill-considered policymaking at the intersection of reproductive technology and human tissue and organ donation. In particular, the novels question whether human dignity, so frequently invoked in this area of bioethical debate, is a stable enough concept upon which to ground regulation or whether it instead is sufficiently manipulable to permit our worst fears and unwarranted assumptions to take the form of reactionary legislation. Reading Picoult alongside Ishiguro advances ongoing debates about whether the products of human reproductive ingenuity should become new tools in the fight against dreaded diseases by asking what we as a society will sacrifice if they do.

* Professor of Law, City University of New York. Many thanks to Caitlin De Sa for her superior research assistance.

1. See, e.g., *Stories and Their Limits: Narrative Approaches to Bioethics*, ed. Hilde Lindemann Nelson (New York: Routledge, 1997), 89–149.
2. See Myriam Sommer, "Avant-Propos," in *Des Enfants Comme Les Autres? La Santé, le Droit et le Bien-Être des Enfants Nés de l'Assistance Médicale à la Procréation* (Paris: John Libby Eurotext, 1996).
3. See *Being Human: Core Readings in the Humanities*, ed. L. Kass (New York: W. W. Norton, 2004), xi, xxi.
4. Rita Charon & Martha Montello, eds., *Stories Matter: The Role of Narrative in Medical Ethics* (New York: Routledge, 2002), vii; see also Rita Charon, *Narrative Medicine: Honoring the Stories of Illness* (New York: Oxford, 2006), x.
5. See Martha Montello, "Novel Perspectives on Bioethics," *Chronicle of Higher Education*, May 13, 2005, at B6. The suggestion that reproductive technology might be a way to address the shortage of human organs for transplantation therapy is suggested by Tony Waldron, "Sibling Saviours," *New Scientist*, Aug. 25, 2007, at 23 (letter to the editor).
6. Jodi Picoult, *My Sister's Keeper* (New York: Atria, 2004).
7. Kazuo Ishiguro, *Never Let Me Go* (New York: Knopf, 2005).
8. Edward White, *Human Fertilisation and Embryology Bill: What Happened?* (2008), 4, available at <http://www.parliament.uk/commons/lib/research/briefings/snsc-04886.pdf>. Sweden has recently granted parents a limited right to create savior siblings. See "Three Bioethical Debates in Sweden," 17 *Cambridge Quarterly of Healthcare Ethics* 261 (2008).

9. "MPs Back Hybrid Embryo Research," BBC News, May 19, 2008, http://news.bbc.co.uk/2/hi/uk_news/politics/7407589.stm.
10. Traditional prenatal genetic diagnostic techniques include ultrasound, amniocentesis and chorionic villi sampling. J. L. Simpson, "PND or PGD: The Place of PGD in Human Medicine," 16 *Reproductive Biomedicine Online* S5 (2008) (supp.).
11. See *R v. Human Fertilisation and Embryology Authority*, [2005] UKHL 28, at [44].
12. See, e.g., Jean Bernard, *La Bioéthique* 23 (Paris: Flammarion, 1994); Robert Boyle & Julian Savulescu, "Prenatal Diagnosis for 'Minor' Genetic Abnormalities Is Ethical," 3 *American Journal of Bioethics* W60 (2003).
13. Cord blood can be used to treat children below the weight of 25 kilograms, but older children will need bone marrow transplantation. See ESHRE Ethics Task Force, "Taskforce 9: The Application of Preimplantation Genetic Diagnosis for Human Leukocyte Antigen Typing of Embryos," 20 *Human Reproduction* 845 (2005).
14. Bernard M. Dickens, "Preimplantation Genetic Diagnosis and 'Savior Siblings,'" 88 *International Journal of Gynecology and Obstetrics* 91 (2005). Adults sometimes donate body parts to their siblings. See Bernard, *supra* note 12, at 22. See, e.g., Lisa Ryckman, "Gift of a Lifetime," *Rocky Mountain News*, July 8, 2006, at 1E. In cases where the prospective donor has insufficient capacity to give informed consent, a court may approve the donation. See, e.g., *Strunk v. Strunk*, 445 S.W.2d 145 (Ky. 1969); *Little v. Little*, 575 S.W.2d 493 (Tex. Ct. App. 1979); *Hart v. Brown*, 289 A.2d 386 (Conn. Sup. 1972).
15. Ethics Committee of the American Society for Reproductive Medicine, "Sex Selection and Preimplantation Genetic Diagnosis," 72 *Fertility and Sterility* 595, 597 (1999).
16. See ASRM, "Sex Selection," *supra* note 15, at 598; ESHRE Ethics Task Force, "Task Force 5: Preimplantation Genetic Diagnosis," 18 *Human Reproduction* 649, 650 (2003). The ethics pronouncements of these societies are not binding on clinics.
17. See ASRM, "Sex Selection," *supra* note 15, at 598.
18. ESHRE, "Task Force 5," *supra* note 16, at 651. "Family balancing" describes the decision of parents to have a child of a certain gender where they already have a child of the other gender or an unequal number of both genders. See *id.*
19. Ethics Committee of the American Society for Reproductive Medicine, "Preconception Gender Selection for Nonmedical Reasons," 75 *Fertility and Sterility* 861–63 (2001).
20. See ESHRE, "Task Force 5," *supra* note 16, at 651; ASRM, "Preconception Gender Selection," *supra* note 19, at 862; ASRM, "Sex Selection," *supra* note 15, at 595–98.
21. See ESHRE, "Task Force 5," *supra* note 16, at 651; ASRM, "Preconception Gender Selection," *supra* note 19, at 862; ASRM, "Sex Selection," *supra* note 15, at 596–97; Human Fertilisation and Embryology Authority, *Sex Selection: Options for Regulation* (2003), quoted in John Harris, *Enhancing Evolution: The Ethical Case for Making Better People* 156 (2007).
22. See, e.g., S. Sheldon & S. Wilkinson, "Should Selecting Saviour Siblings Be Banned?" 30 *Journal of Medical Ethics* 533–37 (2004).
23. ESHRE, "Taskforce 9," *supra* note 13, at 846; see also ESHRE, "Task Force 5," *supra* note 16, at 650.
24. ESHRE, "Task Force 5," *supra* note 16, at 651; see also ESHRE, "Taskforce 9," *supra* note 13, at 846; Françoise Shenfield, "Le Diagnostique préimplantaire en vue de choisir un enfant sauveur de fratrie," 33 *Gynécologie, obstétrique & fertilité* 833 (2005); Guido Pennings, "Saviour Siblings: Using Preimplantation Genetic Diagnosis for Tissue Typing," 1266 *International Congress Series* 311 (2004).
25. See *R v. Human Fertilisation and Embryology Authority*, [2005] UKHL 28, at [37]–[38].
26. ESHRE, "Taskforce 9," *supra* note 13, at 846; G. Pennings, "Creating a Child to Save Another: HLA Matching of Siblings by Means of Preimplantation Genetic Diagnosis," in *Ethical Dilemmas in Reproduction*, ed. F. Shenfield & C. Sureau (Boca Raton: Parthenon, 2002), 51, 60.
27. ESHRE, "Taskforce 9," *supra* note 13, at 846. The courts in *Strunk v. Strunk*, *Little v. Little*, and *Hart v. Brown*, *supra* note 14, applied this doctrine.

28. ESHRE, "Taskforce 9," *supra* note 13, at 846.
29. ESHRE, "Task Force 5," *supra* note 16, at 651; ESHRE, "Taskforce 9," *supra* note 13, at 846.
30. G. Burgio & F. Locatelli, "Ethics of Creating Programmed Stem-cell Donors," 356 *Lancet* 1868 (2000).
31. ESHRE, "Task Force 5," *supra* note 16, at 651; ESHRE, "Taskforce 9," *supra* note 13, at 846.
32. ASRM, "Preconception Gender Selection," *supra* note 19, at 863; cf. ESHRE, "Task Force 5," *supra* note 16, at 651 (emphasizing need to discuss possibility of misdiagnosis).
33. See Pennings, *supra* note 26, at 57; cf. Harris, *supra* note 21, at 156 (commenting on the unlikelihood that sex-selected offspring are selected solely for their gender).
34. *Id.* at 58.
35. J. A. Robertson, "Extending Preimplantation Genetic Diagnosis: The Ethical Debate," 18 *Human Reproduction* 465, 468 (2003).
36. See Pennings, *supra* note 26, at 60; G. Pennings & G. de Wert, "Evolving Ethics in Medically Assisted Reproduction," 9 *Human Reproduction Update* 397, 402 (2003); D. Steinberg, "Response to 'Special Section on Children as Organ Donors' (CQ Vol. 13, No. 2)," 14 *Cambridge Quarterly of Healthcare Ethics* 301 (2005); Harris, *supra* note 21, at 157.
37. See Pennings, *supra* note 36, at 402; cf. John Robertson, "Embryo Screening for Tissue Matching," 82 *Fertility and Sterility* 290 (2004).
38. The President's Council on Bioethics, *Beyond Therapy: Biotechnology and the Pursuit of Happiness* 67 (2003), available at <http://www.bioethics.gov/reports/beyondtherapy/>.
39. *Id.* at 69, 70.
40. *Id.* at 71.
41. The President's Council on Bioethics, *Reproduction and Responsibility: The Regulation of New Biotechnologies* 96 (2004), available at <http://www.bioethics.gov/reports/reproductionandresponsibility/index.html>.
42. *Id.* at 103.
43. See Robertson, *supra* note 35, at 468; see also L. M. Fleck, "Children and Organ Donation: Some Cautionary Remarks," 13 *Cambridge Quarterly of Healthcare Ethics* 161, 162 (2004); W. Glannon & L. F. Ross, "Do Genetic Relationships Create Moral Obligations in Organ Transplantation?" 11 *Cambridge Quarterly of Healthcare Ethics* 153, 155-56 (2002).
44. See Pennings, *supra* note 26, at 63; see also Robertson, *supra* note 37, at 290.
45. See Picoult, *supra* note 6, at 7-8, 19, 72.
46. Picoult has been accused in the British press of "polluting our shores with 'transatlantic schmalz.'" Jemima Lewis, "Morality Tales for the Masses," *The Sunday Telegraph* (London), Apr. 16, 2006, at 18.
47. See Picoult, *supra* note 6, at 143.
48. See *id.* at 100, 136, 231, 269.
49. Sara dismisses Anna's lawsuit as a childish bid for attention. See *id.* at 58, 145, 179, 180, 197.
50. See Shaun D. Pattinson, *Influencing Traits Before Birth* (Aldershot: Ashgate, 2002), 121 ("The use of cloning to provide organ donors is appealing primarily because of the current shortage of spare organs for those in need, causing people to die who could be saved by a transplant.").
51. See *Buck v. Bell*, 274 U.S. 200 (1927).
52. See, e.g., *Skinner v. Oklahoma*, 316 U.S. 535 (1942); *Eisenstadt v. Baird*, 405 U.S. 438 (1972).
53. Press Release, General Assembly, General Assembly Adopts United Nations Declaration on Human Cloning by Vote of 84-34-37, U.N. Doc. GA/10333 (Aug. 3, 2005), available at <http://www.un.org/News/Press/docs/2005/ga10333.doc.htm> (listing states that ban reproductive cloning); Kirstin Matthews, "Overview of World Human Cloning Policies," *Connexions*, Aug. 3, 2007, available at <http://cnx.org/content/m14834/1.1/>. By contrast, there is great regulatory variation as regards therapeutic

- cloning. See S. Pattinson & T. Caulfield, "Variations and Voids: The Regulation of Human Cloning Around the World," 5 *BMC Medical Ethics* 9 (2004).
54. U.N. Doc. GA/10333, *supra* note 53; see *Being Human*, *supra* note 3, at xii, xx, xxiv, xxv, 567–68.
55. Council on Ethical and Judicial Affairs of the American Medical Association, *The Ethics of Human Cloning* (1998), 2–3, available at <http://ama-assn.org/ama1/pub/upload/mm/369/report98.pdf>.
56. See *id.* at 3; Françoise Shenfield, "Human Cloning," 26 *Journal of Medical Ethics* 222 (2000) (book review).
57. Ethics Committee of the American Society for Reproductive Medicine, "Human Somatic Cell Nuclear Transfer," 74 *Fertility and Sterility* 873, 875 (2000).
58. See ASRM, "Human Somatic Cell Nuclear Transfer," *supra* note 57, at 874.
59. See *id.*
60. See *id.* at 874–75; see also Françoise Shenfield, "Cloning: Reproductive, Therapeutic or Not at All?," in *Ethical Dilemmas*, *supra* note 26, at 89.
61. See *Reproduction and Responsibility*, *supra* note 41, at 222.
62. The technique is known as altered nuclear transfer. See I. Hyun & K. Jung, "Human Research Cloning, Embryos, and Embryo-Like Artifacts," *Hastings Center Report*, Sept.–Oct. 2006, at 34, 40.
63. See Hyun & Jung, *supra* note 62, at 40. Cf. R. Lanza et al., "The Ethical Validity of Using Nuclear Transfer in Human Transplantation," 284 *JAMA* 3175, 3178 (2000).
64. See Hyun & Jung, *supra* note 62, at 37. See also Lanza et al., *supra* note 63, at 3175 (proposing the substitution of the term "cell replacement through nuclear transfer (CRNT)" for "cloning" when referring to stem cell research). The term "ovasome" has also been suggested. See Ronald Green, "Five Ethical Questions for SCNT Stem Cell Research," 9 *Minnesota Journal of Law, Science & Technology* 131, 137 (2008).
65. Ishiguro, *supra* note 7, at 4, 30.
66. "Kazuo Ishiguro with Maya Jaggi," in *Writing Across Worlds: Contemporary Writers Talk*, ed. Susheila Nasta (Abingdon & New York: Routledge, 2004), 164.
67. "Kazuo Ishiguro," *supra* note 66, at 168.
68. "Kazuo Ishiguro," *supra* note 66, at 160.
69. *Id.*
70. *Id.*
71. Joyce Carol Oates, *Uncensored: Views and (Re)views* (New York: Ecco Press, 2005), 89.
72. *Id.* at 88.
73. Ishiguro, *supra* note 7, at 276–77, 286–87.
74. Ishiguro, *supra* note 7, at 37.
75. *Being Human*, *supra* note 3, at xxv.