Lisa Campo-Engelstein · Paul Burcher
Editors

Reproductive Ethics II

New Ideas and Innovations

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Susan B. Levin is Roe/Straut Professor in the Humanities and Professor of Philosophy at Smith College. The focus of her research is bioethics. In that work, she often draws on her extensive background in Greek philosophy, which is reflected in many articles and two books, including *Plato's Rivalry with Medicine: A Struggle and Its Dissolution* (Oxford 2014). Though she has also written on the issue of organ transplantation, her current work centers on the debate over human enhancement. Her particular concern is advocacy of vigorous enhancement (i.e., transhumanism), and in recent publications, she has critiqued transhumanists' claims in a range of areas. At this time, she is writing a book in which she fundamentally challenges transhumanists' arguments, assumptions, and methodologies on philosophical and scientific grounds.

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Reproductive Ethics: Introduction

Lisa Campo-Engelstein and Paul Burcher

Until quite recently human reproduction was considered an entirely natural process, and the ethics of reproduction were governed more by cultural mores and religious strictures than by any serious philosophical or empirical inquiry. However, more recently reproductive ethics has exploded as a field for several reasons. At a cultural level, many things taken for granted a generation ago, including the increasing medicalization of birth and the heteronormative two-parent nuclear family, have been challenged, and new possibilities have arisen from these now contested ideas. It is important to remember that the explosion of reproductive ethics is as much from new thinking as it is from new technologies, and, at least in regard to reproductive possibilities for the LGBTQ community, it may well be fair to say that it is our new thinking that then led to new technological explorations.

This compilation, we hope, touches upon many of the pressing questions in our field. Nonetheless, we recognize that no single volume of essays could possibly cover every aspect of our exciting field. As we underlined in our first volume as well, this is a field that benefits from a multidisciplinary approach, as its questions are informed by law, philosophy, anthropology, public health, and of course, medicine. From gene editing to birth support, reproductive ethics is rapidly evolving, and one need only consider whether any of the following chapters could have been written 5 years ago to recognize the truth of this.

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Genetics, Eugenics, and Reproduction

There is significant debate in the bioethics community regarding whether it is ethical to genetically engineer children. Yet, genetically modified children have been created via three-person IVF since the 1990s. In light of this, Ellen Hunt Botting, in "*Frankenstein* and the Question of Children's Rights *after* Human Germline Genetic Modification," is interested in exploring not whether it is ethical to create genetically engineered children, but rather to examine the rights genetically modified children should have. She turns to Mary Shelley's 1818 novel *Frankenstein*, the prototype for speculative and science fiction on the ethics of the artificial creation, to argue that, regardless of their reproductive circumstances or genetic features, children have fundamental and universal rights to both parental love and nondiscrimination.

Jennifer Murphy and Jazmine Gabriel, both clinical genetic counselors, address the thorny issues of reporting secondary findings in prenatal genetic testing in their chapter, "The Ethical Complexity of Using Whole-Exome Sequencing to Detect Adult-Onset Conditions in the Prenatal and Pediatric Settings." Recent recommendations by the American College of Genetics and Genomics (ACMG) upend previous ethical guidelines that discouraged giving findings of adult onset genetic conditions in a pediatric or prenatal setting. They explain the reasoning behind the ACMG change, but argue that the potential harms to children and the violation of a child's right "to an open future" are ultimately more salient than the benefits of giving these results.

Susan Levin's critique of transhumanists in "Creating a Higher Breed: Transhumanism and the Prophecy of Anglo-American Eugenics" is both extensive and disturbing. Transhumanists support bioenhancement of the human species by embryo selection and other technological means thereby supplanting evolution by natural selection with human agency. Transhumanists make two claims that Levin systematically refutes. The first is a total discontinuity of thought with earlier eugenicists including Anglo-American figures, and of course, the Nazis. She demonstrates the many shared ideas between historical eugenics and the transhumanists to deny their claims of independence. The second, perhaps more disturbing argument made by Levin, is that while transhumanists describe their project as voluntary and individual, the success of their project would require state intervention and is at odds with liberal democracy. The utilitarian reasoning and references to public health successes as analogous to their project demonstrate that their real intent is not to allow this to remain at the level of choice for individual couples, but rather to "encourage," "subsidize," and eventually mandate enhancement. With CRISPR, our technological power to shape our genome may rapidly expand, and as Levin points out any coercive use of this power may ultimately, or even rapidly erode both our personal freedoms and our democratic traditions.

Exploring Infertility and the Right to Reproduce

Nicholas Brown argues in "One is the Loneliest Number: How the WHO's Redefinition of Infertility Provokes Contestations of the Body and the Body Politic" that it is a conceptual and normative error to include single persons in the WHO definition of infertility. He first addresses the issue that infertility is considered a disability by the WHO and that extending the definition of infertility to single persons would then extend the concept of disability to people with no physical limitation. Drawing from the disability literature, he sides with Riddle and others who argue it is a mistake to claim that being disabled is only a social phenomenon. To do this is to ignore or deny the ontological reality of physical limitations that underpin what we mean by disability. His second point is that the underlying logic to this claim is that there is a right to reproduce, and that this is an individual right. Brown points out that parenting, which is the outcome of reproduction, is not an individual endeavor, and that we have a societal responsibility to ensure that children are raised properly. Thus, to enshrine a new right of parenthood based upon an individual's claim is to miss the nature of parenting as both a right and a duty, and as both individual and communal.

In contrast to Brown, Weei Lo and Lisa Campo-Engelstein argue in "Expanding the Clinical Definition of Infertility to Include Socially Infertile Individuals and Couples" that single people and LGBTQ couples should be viewed as infertile. Distinguishing between physiological infertility and social infertility (i.e., infertility due to relationship status, such as being single or being in a same-sex couple), they argue that current clinical definitions of infertility uphold the heteronormative values by failing to recognize social infertility. Given that single individuals and LGBTQ couples want genetically related children, the psychosocial harms of infertility are just as significant for them as they are for heterosexual couples. They assert that states with infertility insurance mandates should provide the same treatment to socially infertile individuals as physiologically infertile heterosexual couples currently receive.

Philipa Friedman, writing from an ecofeminism perspective, addresses the problems of overpopulation and overconsumption in the global west in "Social Responses to the Environmental Impact of Reproduction in the Global West: A Critique of Christine Overall's 'Overpopulation and Extinction.'" In her critique of Christine Overall's *Why Have Children*?, she first argues that Overall's individualistic and moralistic response to this problem is both impracticable and fails to acknowledge the way in which the oppression of women actually plays a causal role in unintended pregnancies even in developed nations. Because Overall accepts a negative right of all couples to procreate, she believes the impetus for reducing population growth must ultimately be an individual choice. Friedman's response is to accept the right of procreation, but to reject the notion that only individual ethical choices can then be brought to bear on this problem. Looking at demographic data, Friedman shows that education and opportunity allow poorer women and women of color to choose to have smaller families and fewer unintended pregnancies. Thus, the solution to environmental degradation from overconsumption and overpopulation is inextricably linked with elevating the status of women.

Reflections on Assisted Reproductive Technologies

Karey A. Harwood, in "Decentering Whiteness in Feminist Bioethics: Assisted Reproductive Technologies (ART) as an Illustrative Case," claims that not enough progress has been made in "decentering" whiteness in bioethics, including in feminist bioethics. Using ART as an illustrative case, she shows how ART functions within a framework of "normative whiteness," which marginalizes the experiences of people of color and perpetuates racial disparities in both access to ART and in treatment outcomes. Harwood argues that feminist bioethics needs to put race at the center of analysis and makes recommendations for achieving this in a sustained and meaningful way.

In "New Pitchforks and Furtive Nature," Daniel Maher addresses the interesting conundrum of reproductive ethics, namely, that many of our arguments for or against new technologies make reference either implicitly or explicitly to the priority of "nature" despite the fact that the ontology of "nature" itself is elusive. That is, we use it as a reference point without having a clear idea of what we mean by it. While acknowledging the temptation to make the "natural" a point of reference, he shows the many problems associated with trying to define or capture it. Both cultural overlay and a scientific versus theological worldview yield radically different answers, and accordingly different ethical conclusions despite all claiming to begin in "nature." By exploring the implications of challenging technologies such as mitochondrial transfer and cloning, he is, in the end, making a plea that we become clearer regarding whether there are "essential" aspects to human reproduction that should not be compromised in our technological leaps forward into a "Brave New World."

In "Assisted Reproductive Technology & the Proliferation of Parents: The More, the Merrier?," Greg Yanke explores, from a legal and ethical perspective, whether there should be limits to the recognition of multi-parent families. From a legal perspective, he highlights that several American and Canadian jurisdictions have recognized that a child can have more than two parents, though he claims that a constitutional right to a multi-parent family structure seems unlikely. From an ethical perspective, he draws on both principlism and narrative ethics to argue that the interests of the child should be at the center of any deliberation about family structure and should take precedence over the preferences of the parents.

Reproductive Perspectives, Practices, and Education

The topic of fetal personhood is a contentious one in bioethics and in mainstream cultural debates. In “Reconceiving the Human Fetus in Reproductive Bioethics,” Sallie Han, Tracy K. Betsinger, Michaelyn Harle, and Amy B. Scott turn to cultural anthropology and bioarchaeology to show that fetal personhood is not a given, but rather is actively negotiated and ascribed through social and cultural processes. Based on ethnographic field research and bioarchaeological studies in postmedieval Poland and prehistoric Tennessee, they provide historical and cross-cultural perspectives on the status of fetuses to highlight that how and whether personhood was ascribed to fetuses is both historically and culturally situated.

Corinne McLeod explores the ethics of crisis pregnancy centers (CPCs) in “The Ethics of Evangelism: Why You Can’t Be a Good Physician and Support Crisis Pregnancy Centers.” Taking a principlist approach, she argues that CPCs are unethical because they inhibit autonomy through misleading and false information, they prioritize preventing abortion over avoiding harm and promoting good for the patient, and they take advantage of vulnerable patients. For these reasons, she asserts that medical professionals should not only not support CPCs, but they should also advocate against them because they can undermine the physician/patient relationship.

Employing a reproductive justice lens, Kathryn Mishkin and Luisa Fernandes, in “Doulas as Agents of Reproductive Justice Who Promote of Women’s International Human Rights: An Evidence-Based Review and Comparative Case Study between Brazil and the United States,” examine the ways in which doulas uphold the goals of the international human rights community. They assert that doulas serve as agents of reproductive justice by advancing maternal health and women’s empowerment in three ways: improving health outcomes, promoting women’s control over their health, and reducing cost-related health disparities. Additionally, they provide a cross-cultural comparison of doula work in two countries, Brazil and the United States, to explore the successes and challenges it faces based on different health systems, cultures, and stages of development.

In “Reproductive Flourishing: A Framework for Teaching Reproductive Ethics in Clinical Education,” Amy Michelle DeBaets explores various ethical frameworks—natural law, reproductive rights, reproductive justice, and reproductive flourishing—that are typically employed in teaching clinicians-in-training about how to aid their patients in making difficult reproductive decisions. Presenting and analyzing three case studies, she shows that the first three ethical frameworks are less useful to clinicians-in-training because they tend to emphasize the permissibility or impermissibility of particular choices or focus on the broad policy level. DeBaets favors the reproductive flourishing framework because it centers on meeting the needs of patients while also enabling clinicians-in-training to recognize and reflect on their personal reproductive values and goals.

Part I

Genetics, Eugenics, and Reproduction

Frankenstein and the Question of Children's Rights *After* Human Germline Genetic Modification

Eileen Hunt Botting

Introduction

A skeptical response to the idea of using genetic engineering to make human clones or designer babies is to compare it to "science fiction" (Phillips 2015: 116). The less studied history is that human germline genetic modification—or HGGM (Pham 2006: 134)—has already happened, through various successful reproductive applications of techniques of three-person IVF since the late 1990s. While bioethicists have reached for Nathaniel Hawthorne's *The Birth-Mark* (1843) for public literary reflection on ethical issues surrounding HGGM (PBC 2002), they should not overlook Mary Shelley's *Frankenstein; or, the Modern Prometheus* (1818)—the prototype for all speculative and science fiction on the ethics of the artificial creation, modification, and transformation of human life (Brem and Anijar 2003: 22; Chan 2009: 398). By reading *Frankenstein* in light of the two-decade history and fast-paced trajectory of HGGM, we can treat the novel as an ethical resource for twenty-first century debates about the use of biotechnology (such as three-person IVF or the recently invented CRISPR-Cas9 tool for genome editing) to permanently and heritably modify the human genome. At the heart of Shelley's story is a child-centered thought experiment, which projects the devastating effects of abandonment, neglect, and abuse on children, no matter how, from what, or by whom they are made (Botting 2017: 23). By running this thought experiment, readers of *Frankenstein* have the ethical opportunity to sympathize with Frankenstein's Creature and to consider his fundamental and universal rights as a child to parental love and nondiscrimination regardless of reproductive "circumstances" or "features" of genesis (Shelley 2012: 142, 49).

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The History of HGGM

During the late 1990s in the United States, fertility doctors accomplished HGGM as a by-product of an early, experimental form of three-person IVF (Cohen et al. 1997). To boost the mother's fertility, the "ooplasmic transfer" technique (OT) injected the mother's egg with the ooplasm of a donor egg, then fertilized it with the father's sperm. OT produced embryos with the DNA of the mother and father, plus some mitochondrial DNA (mtDNA) of the donor (Barritt et al. 2001). In 2001, it was reported that 23 children had been born in the United States from OT; the same year, the FDA halted its further use due to concerns about its safety for the development of the children made from it, especially due to heteroplasmy (Knoepfler 2016: 89). One of the pioneers of OT, Dr. Jason Barritt, described it as the first successful reproductive use of biotechnology to accomplish human "germline genetic modification" (Barritt et al. 2001). It has since been estimated that OT produced at least 58 (Kirkey 2015) and perhaps upward to 100 children around the world at the turn of the twenty-first century (Weintraub 2013). Due to having the DNA of their parents in addition to some mtDNA of the donor egg, these children of OT are technically genetic chimeras composed of cells from different zygotes.

Despite this unprecedented step in HGGM, one of the (now young adult) children made by OT, Alana Saarinen, has downplayed the biological significance of her distinctive reproductive circumstances and genetic features. Regarding her mother's egg donor, she said, "I wouldn't consider her a third parent, I just have some of her mitochondria" (Pritchard 2014). Saarinen's comment suggests that OT and other popularly described "three-parent IVF" techniques are more accurately described, medically and ethically, as "three-person IVF," because genetic parentage does not necessarily translate into social parentage, in the eyes of children, parents, donors, researchers, doctors and other healthcare providers, or the law (Knoepfler 2016: 91).

Since the FDA halted the further use of OT in 2001, two forms of mitochondrial replacement therapy (MRT) have been developed. MRT strives to avoid the potential of OT to introduce heteroplasmy and related developmental disorders by effectively replacing (not supplementing) the intended mother's mtDNA with those of a donor egg (Mitalipov and Wolf 2014: 5–6). In China in 2003, US-based Dr. Jamie Grifo controversially tested a second three-parent IVF technique—"pronuclear transfer" (PNT)—which moves the pronuclei of the intended parents' zygote into an enucleated zygote made from a donor egg and the intended father's sperm. This attempt failed, ending with the loss of several fetuses (Zhang et al. 2003; Knoepfler 2016: 93). In January 2017, fertility doctors in Ukraine reported the first baby born from PNT for the express purpose of boosting fertility, not preventing mitochondrial disease (Roberts 2017).

Now that Britain legalized in 2015 another form of three-parent IVF—"maternal spindle transfer" (MST)—which transfers the intended mother's spindle of nuclear DNA into an enucleated donor egg prior to fertilization in order to prevent the genetic transmission of mitochondrial disease, there will be many children born with the DNA of three people and who will be capable of passing down this genetic legacy to future generations through the maternal line (Castle 2015). In April 2016, the first baby was born from MST to Jordanian parents who had suffered repeated loss of pregnancies and young children due to a deadly mitochondrial disease, Leigh syndrome (Zhang et al. 2017). They sought treatment in Mexico from a team of US fertility doctors (led by Dr. John Zhang) aiming to avoid regulation of their innovative technique (Sample 2016). In 2017, the first MST babies are expected in Britain, where the law permits the use of the procedure only for the prevention of mitochondrial disease, not solely for boosting fertility.

Along with prospective HGGM through genome editing (such as with the CRISPR-Cas9 biotechnology invented in 2012–2013), the widespread use of MST and PNT for reproductive purposes could potentially lead to more GM children and eventually the development of a new evolutionary line (Knoepfler 2016: 7). CRISPR-Cas9 is a biotechnology that can delete or edit particular genes and thus accomplish HGGM at the level of nuclear DNA. CRISPR-Cas9 thus has the potential to go far beyond the alteration of mtDNA (as in the three-person IVF techniques) to the modification of the basic genetic blueprint for human development. While babies made from MST and PNT have only 0.1% of their total DNA from an mtDNA donor (Mitalipov and Wolf 2014: 7), CRISPR-Cas9 could be used to make germline modifications to the other 99.9% of human DNA—changes which would be heritable down the maternal and paternal lines.

In theory, CRISPR-Cas9 and other genome editing biotechnologies could be used to permanently delete, select, or enhance particular genetic traits in people so as to create a new kind of GM person. In 2017, scientists reported the making of a 4-week-old "part-human chimera" by using CRISPR-Cas9 to enable the development of human pluripotent stem cells into organ tissue within a pig embryo (Wu et al. 2017). Although the CRISPR-Cas9 technology has not been for purposes of human reproduction, it has been used in China in 2015 for research into the efficacy of removing a human gene for a blood disease (Knoepfler 2016: 1), as well as approved in Britain in 2016 for research into human embryonic development (Callaway 2016). In August 2017, an international team of scientists reported their successful use of CRISPR-Cas9 to repair genetic mutations in human embryos that would otherwise cause a common heart defect (Ma et al. 2017). Driving home the urgency of the ethical and political issues raised by the wide-scale creation of GM children, molecular biologist Guoping Feng recently estimated that CRISPR-Cas9 gene-edited babies were only 10–20 years away (Regalado 2015).

How *Frankenstein* Relates to the Ethics of HGGM

Taking as my starting point the actual creation of GM children in the recent past and its likely growth in the near future, I look back to *Frankenstein* as an ethical resource for conceptualizing the rights of such children. *Frankenstein* is a powerful speculative fiction for projections of the potential consequences of using biotechnology to intervene in human evolution (Dominy and Yeakel 2017). The novel and its many adaptations have also generated a "metaphorical shorthand" for a core argument of medical and research ethics: the danger of playing God through science (Chan 2009: 398). Perhaps even more importantly, however, analysis of the complex novel yields moral and political ideas that relate directly to the contemporary issue of defining the rights of GM children.

While political theorists such as Francis Fukuyama (2002), Jürgen Habermas (2003), and Michael Sandel (2007) have famously engaged the forward-looking ethical issues surrounding the long-term possibility of some forms of genetic engineering (such as human clones or designer babies), they overlooked the actual practices of human genetic engineering that were documented in medical journals at the turn of the twenty-first century (Cohen et al. 1997; Barritt et al. 2001; Zhang et al. 2003). In contrast to the futuristic approaches to bioethics taken by leading political theorists, I employ an interdisciplinary medical humanities approach—bridging historical, literary, and philosophical viewpoints—to engage the moral and political questions raised by genetic engineering of children in the recent past.

There is a growing interest in *Frankenstein*'s relevance to bioethics, medical ethics, and research ethics (Davies 2004; Jonsen 2011; Harrison and Gannon 2015). In a more political vein, I highlight *Frankenstein*'s conceptual power to reframe the debate on the ethics of genetic engineering such that it does not overlook urgent questions of children's rights in the here and now. After 20 years of successful reproductive use of three-person IVF, and the recent use of CRISPR-Cas9 for research on human embryos in China and Britain, the only hard question is no longer, "Should science genetically engineer children?" (Fukuyama 2002; Habermas 2003; Sandel 2007). An equally difficult question is "What are the rights of the GM child?" (Mason and Ekman 2017: 57–58).

Shelley wrote a novel in 1816–1817 that bears precisely on this vital ethical question: what are the rights of a child brought to life from the parts of human and other animals in a lab by a scientist through a kind of ART? What's more, she gave voice to the radical idea of the rights of a supposedly "monstrous" child through the unprecedented literary character of Frankenstein's Creature. Shelley was visionary in her imagining of the Creature—who, as we shall see, can be compared to either a chimeric or a hybridic child made through biotechnology. Even more radically, she had the Creature express a "right" as a child "to live in the interchange of those sympathies necessary for my being" (Shelley 2012: 159). She dramatized the problem of the denial of rights to *any* child—regardless of their reproductive circumstances or features of genesis—by having the neglected and abandoned Creature demand of his father-scientist a right as a child to share love with a parent or fitting substitute.

Twenty-first century bioethicists have begun to grapple with the moral issues surrounding the creation of "part-human" chimeric and GM embryos (Baylis and Robert 2007). Yet those who have argued for OT, MST, or PNT's moral impermissibility (Baylis 2013) or permissibility (Palacios-González 2016) have not touched the issue of the *rights* of the GM children made from these or prospective forms of HGGM (such as through CRISPR-Cas9). While moral and technological caution is both prudent and necessary when it comes to any form of scientific experimentation with the human genome (Sandel 2007), it is of equal moral and political importance to consider the rights of GM children who have been or will be made (Mason and Ekman 2017: 20–21).

Bioethicists should take into account not only children's rights in vitro, as future persons with "open futures" or as potential parents (Greely 2016: 225–237), but also their rights *in childhood*—namely, during the stage of development between birth and adulthood. The traditional bioethical focus on justifying the right *not* to be genetically modified skews attention toward the dignity and rights of zygotes, blastocysts, embryos, and future persons (Habermas 2003: 63; Pham 2006: 150; Darnovsky 2010) and away from the articulation of the civil and human rights of actual GM children and other "babies of technology" (Mason and Ekman 2017: 195–202). *Frankenstein* proves to be an indispensible ethical resource for making this profound yet neglected political point: the rights of actual GM children should not be overlooked in the race to innovate and expand HGGM for purposes of infertility treatment, human enhancement, and the prevention or elimination of disease. To heed Habermas's warning of the dangers of philosophical abstraction in bioethics, we ought to read Shelley's novel as a classic reminder that "the moral community of free and equal subjects of human rights does not form a 'kingdom of ends' in the noumenal beyond, but remains embedded in concrete forms of life and their ethos" (2003: 37). In raising the question of children's right to love, Frankenstein's Creature embodies the value of speaking of children's lives in concrete and plural terms.

Mary Shelley's Thought Experiment on Early Child Development

The core of the narrative of *Frankenstein* is a cascade of five thought experiments on the rights of the child:

1. What would it mean for a child to be made absolutely motherless—without any biological or social mother?
2. What would happen if the child were so ugly that no one loved him, including the father-scientist who made him without any mother?
3. What if the child had the physical and mental strength to survive exposure at birth?
4. What if the child suffered total abuse by society in addition to his utter motherlessness and lovelessness?
5. What enduring obligations would the child's father have toward the abused and abandoned child, and what would be the limits of those obligations and the child's corresponding rights? (Botting 2017: 23)

Thought Experiment 3—which treats the conditions for flourishing in early child development—is especially relevant to debates on the ethics of HGGM. Thought Experiment 3 also corresponds to the literal center and figurative heart of the novel: the Creature's story of how he merely survived and failed to emotionally and socially thrive due to the discrimination he suffered as a result of what he calls, after reading his father's laboratory journal, the "disgusting circumstances" of "my accursed origin" (Shelley 2012: 142). Thought Experiment 3 shows that any child—no matter the reproductive circumstances or the special features derived from this origin—needs and deserves love from a parent or fitting substitute in order to flourish (Bowlby [1969] 1982: 177–209; Liao 2015: 85–97).

Other aspects of the cascade are relevant to the issue of determining Victor Frankenstein's parental obligations toward the Creature and the Creature's corresponding rights as a child. Thought Experiment 1, for example, renders Victor solely responsible for making his Creature. By reducing the number of parents to one, and eliminating any biological or social mother, this counterfactual scenario hones the reader's attention upon the primary responsibility of Victor, a man and a scientist, for his Creature.

Thought Experiment 5 teases out the ethical implications of Victor's primary responsibility for his Creature, by demarcating the limits of a parent's duties toward a child and a child's rights toward a parent. While Victor has an enduring obligation to provide or at least arrange for his child's sharing of love with a parent or a fitting substitute, he does not have a duty to satisfy the Creature's demand to make him an equal female companion. The latter arrangement would violate the prospective equal female creature's freedom as it would not take into account her equal right to choose whom her friends and companions should be.

While the Creature has no instrumental (and potentially exploitative) right to have a female companion made for him by his father-scientist, he has a fundamental right as a child to share love with a parent or fitting substitute during childhood. Despite his unfitness and incapability to be a loving parent to his child, Victor cannot evade this fundamental duty to at least arrange for a parent or fitting substitute to share love and companionship with his Creature for the sake of his healthy and happy development as a child. The endurance of this fundamental parental duty and correlative child's right—despite conditions of parental neglect and abuse—is movingly depicted by the Creature's harrowing cries of loneliness and sorrow by his father's coffin. The central "injustice" of the novel is that Victor fails to fulfill even the minimal duty to arrange a fitting substitute before his death. Following from this injustice is the tragedy of leaving his utterly abandoned—and finally suicidal—child without a single affective tie to humanity (Shelley 2012: 160).

Despite their greater narrative complexity, such literary thought experiments work in a similar way as philosophical and scientific thought experiments (Chan 2009: 398). Literary thought experiments turn readers into "armchair philosophers" who can manipulate, isolate, and puzzle through the relevant moral and political issues at stake in a thorny ethical debate (Swirski 2007: 96, 108–109). *Frankenstein*'s cascade of thought experiments has the conceptual power to help medical providers, philosophers, lawyers, and policy makers address the question of how to theorize the scope and limits of children's rights after HGGM.

Why Compare Frankenstein's Creature to a GM Child?

Before we assess the relevance of *Frankenstein* to the contemporary issue of the rights of GM children, we need to establish why it is reasonable to compare the Creature to a GM child in the first place. It is valid to compare the Creature with GM children today, both in medical and in social terms, but only with respect to their circumstances of reproduction. It would be wrong to suggest that all GM children are like the Creature, who becomes a murderer due to his worst-case scenario of total lovelessness, abuse, and neglect as a child (see Thought Experiments 2 and 4).

There are eight aspects of the Creature's character that arise from his reproductive circumstances. Together and separately, these eight aspects show the Creature's rough social and medical similarities to GM children today:

1. *The Creature is a child.* He is brought into the world as a vulnerable being who is dependent on experiencing loving care with a parent or fitting substitute for his happy and healthy development as a child.

   GM babies are children. They have the same social status and needs as other children, especially to parental love and other basic conditions for their healthy and happy development during childhood.
2. *The Creature could be either a hybrid or a chimera.* The Creature could be a kind of asexually produced hybrid made from the parts of human and other animal corpses and fused together through some unspecified combination of medieval alchemy and modern chemistry (Shelley 2012: 30–34). He also could be a new kind of mechanically assembled chimera composed of human and other (likely mammalian) animal cells from different zygotes (Shelley 2012: 34–36).

   GM children made by three-person IVF are chimeras. GM children made from OT, PNT, or MST are a new kind of genetic chimera with the DNA of three people (Knoepfler 2016: 86).

   GM children could be hybrids or (part-human) chimeras. GM hybrids can be made through genetic modification of gametes or by genetic modification of distinct species that can interbreed (Knoepfler 2016: 49–53, 88, 223). "Part-human chimeras" (Baylis and Robert 2007), such as pig embryos infused with human stem cells in order to grow human muscular tissue, have been made with the assistance of CRISPR-Cas9 (Wu et al. 2017).
3. *The Creature is a modified human.* The Creature was not made through sexual reproduction, but rather through a complex process of donation, assembly, and reanimation of parts of human and other animal corpses. In order to facilitate the success of his experiment in the artificial creation and modification of life, Victor made the Creature of "a gigantic stature…about eight feet in height, and

proportionally large" (Shelley 2012: 33). He also made the Creature with the features of greater strength and resilience than typical humans.

GM children are modified humans. Their DNA is modified by IVF doctors. MST and PNT can be used to eliminate potentially lethal mitochondria from children, thus increasing their viability and enhancing their resilience to genetic disease (Mitalipov and Wolf 2014). CRISPR-Cas9 could be used to modify the genomes of children in a way which could dramatically change their features and capacities in comparison to typical human children (Knoepfler 2016: 233).

4. *The Creature is made from parts of donors.* Because Victor takes human parts from "vaults" and "charnel houses" in the cover of the "night," he evades legal regulation (including issues of consent) with regard to the gathering of some of his "materials" (Shelley 2012: 31, 34). His recourse to the "slaughterhouse" for nonhuman parts and the "dissecting room" for human and nonhuman parts was legal if he did not steal them (Shelley 2012: 34). Either way, the donors were anonymous and non-consenting.

   GM children are made from the parts of donors. Three-person IVF makes GM children from the gametes of three people, including an egg donor, the intended mother, and the intended father (or a sperm donor). CRISPR-Cas9 could be used to make GM children from donor gametes, artificial gametes, or the gametes of intended parents. In all cases, donors may be anonymous or not, depending on legal regulation. The formal consent of intended parents and donors is mandated as part of the process of any form of IVF where it is legally regulated. Donors may be exploited, manipulated, or otherwise harmed, thus compromising or invalidating formal consent from a moral perspective (Baylis 2013).

5. *The Creature is made through a kind of biotechnological intervention*. It probably involved the application of electricity to the giant corpse assembled from donor parts.

   GM children are made through a number of biotechnological interventions. These include specialized techniques of IVF and MRT, and likely in the near future, stem cell research and genome editing.

6. *The Creature is made in a laboratory.*

   GM children are made in a laboratory. IVF zygotes are conceived in a petri dish and stored in a laboratory for several days of embryonic development. Embryos are transferred into the womb of an intended mother or surrogate in the setting of a medical clinic, usually 3–5 days after fertilization. GM embryos are modified prior to transfer.

7. *The Creature is made through ART.* He is made through a completely asexual kind of ART, not through sexual intercourse or technologically assisted sexual reproduction such as artificial insemination or IVF.

   GM children are made through ART. They are made through IVF, not sexual intercourse or artificial insemination.

8. *The Creature's features are selected as perfect.* Victor "selected his features as beautiful," but runs away from his animated Creature in fear of his "hideous" countenance and "deformity of its aspect" (Shelley 2012: 35–36, 50).

> *GM children have a feature selected as perfect.* The goal of OT was to use the fertility-boosting ooplasm of a donor egg to enable infertile women to have a child made from their nuclear DNA. A goal of MST and PNT is to eliminate mitochondrial disease through such artificial selection. CRISPR-Cas9 could expand and morally complicate this perfectionistic (and potentially eugenic) aspect of HGGM by selecting particular genes to delete or edit for the sake of cognitive, moral, or physical enhancement of children, not solely the boosting of parental fertility or the prevention of genetic disease. All forms of HGGM can cause birth defects, contrary to the perfectionistic intentions of the scientists and doctors who make the modifications (Sandel 2007: 67).

Comparing the Creature to a Part-Human Interspecific Chimera: Ethical Implications for Children's Rights

Interspecific "chimeras are creatures with cells, tissues, or organs from individuals of two different species" (Baylis and Robert 2007: 41). The Creature can be compared to a "part-human" interspecific chimera, which is "morally controversial" when it comes to the question of how it might impact human reproduction: what if "a chimeric mouse with human sperm" mated with "a chimeric mouse with human eggs"? (Baylis and Robert 2007: 42). This ethical scenario is akin to the counterfactual conditional that Victor proposes in Thought Experiment 5, regarding the possible consequences of the mating of the Creature and the (as yet unanimated) equal female companion: what if the creatures reproduced and made a "race of devils" capable of destroying the "species of man"? (Shelley 2012: 119). In his apocalyptic speculation of human extinction caused by a technologically made competitor species, Victor presciently articulates the "competitive exclusion" argument against HGGM (Fukuyama 2002: 216; Dominy and Yeakel 2017: 107).

At the same time, Victor makes a number of questionable (and perhaps self-serving) assumptions, which reveal some of the ethical limitations of the competitive exclusion argument against HGGM. First, it is not clear that the Creature or his proposed equal female companion would be fertile (they may be infertile hybrids, like mules), or even that either will want to have sex or reproduce together. Even if Victor as a scientist was somehow certain that he had designed the Creature as a fertile interspecific chimera, he presumably could have made the female infertile prior to animating her—although this scenario raises its own set of ethical issues concerning modification of embryos, fetuses, or children with regard to fertility. Finally, it is not clear that the creatures or any offspring would necessarily be destructive toward the human species, intentionally or not. From an evolutionary perspective, one must surmise that their greater strength and resilience would increase their longevity relative to humans (Dominy and Yeakel 2017: 107). Combined with breeding on a broad scale, the presumed longevity of the creatures could produce a competitor species for humans in the long run (Dominy and Yeakel 2017: 108).

In the Creature's single use of the term "mate," he situates himself ambiguously between "each man" and "a wife" on the one side and "each beast" and "his mate" on the other (Shelley 2012: 120). Standing in the middle between man and beast and their respective practices of marriage and mating, the Creature asks for an equal female "companion" with whom he could escape far from human beings and civilization to the "wilds of South America" where they would live alone, in a "peaceful and human" way, as vegetarian nomads, with little environmental footprint, making "our bed of dried leaves"—a symbol of infertility (Shelley 2012: 101–103).

Let us grant for the sake of argument (1) Victor's assumptions about the creatures' reproductive powers and desires, (2) the apocalyptic consequences that follow from them, and (3) that he has a duty to stop their reproduction for the sake of the preservation of the human species. Even granting these assumptions, it does not follow that Victor has a duty to (1) deny his Creature a nonreproductive companion of some sort who could be a fitting substitute for a parent, or (2) destroy the female rather than animate her without reproductive powers. This chain of moral reasoning is relevant to scientists who make part-human interspecific chimeras, with or without reproductive powers (Wu et al. 2017).

Hearing the Creature: Frankenstein *and the Articulation of the Rights of GM Children*

The story of the artificially made and modified Creature suggests that children's rights are in fact the most fundamental form of rights, because each and every person—regardless of origins, features, or capacities—begins life as a vulnerable child. These fundamental rights of the child include, first and foremost, a right to share love with parents or fitting substitutes, for such love is essential to all children's healthy and happy development (Liao 2015: 74). As Shelley's Creature poetically demands of his father-scientist, he has a "right" as a child to "live in the interchange of those sympathies necessary for my being" (Shelley 2012: 101). Without love of a parent or fitting substitute, the Creature fails to emotionally thrive, as any young child would, despite his incredible strength, size, capacity for cognitive development and language acquisition, and ability to physically survive on his own. A chimera or hybrid of human and other animal parts, the Creature is pushed outside of the human community due to his hideous deformity, and made into the monster he was originally, tragically mistaken to be by his maker (Mellor 1988).

When we focus on the need to reassess children's rights after genetic engineering, Shelley's novel emerges as a resource for thinking through the rights of all children (artificially made or modified or not) to both parental love and nondiscrimination. As for the child's right to love, the story of the Creature disputes the approach of the most prominent defender of the "right to be loved," S. Matthew Liao (2015). Liao hypothetically derives and justifies all children's rights (including the passively formulated right "to be loved") from an as yet un-sequenced human gene for moral agency (2015: 17–25). Both the counterfactual case of the Creature and the factual case of GM children challenge such deterministic approaches to grounding children's moral status as rights-holders upon a fixed conception of the human genome. First, Liao's deterministic argument could arbitrarily exclude some children from rights solely because of their biological differences from the current norm for human genomic content. By rooting human agency and capability for rights-holding in a hypothetical gene, Liao runs the risk of excluding GM children from the rights they need for healthy and happy development from the very outset of life, because they had the wrong gene deleted or modified in vitro. Second, his deterministic argument projects a false image of the human genome as static, rather than evolving in part due to the use of ART. GM children made from OT, MST, and PNT are not unhuman or nonhuman, but rather "a new kind of human being" (Knoepfler 2016: 87). The same may be said of the Creature—while he is seen as a "savage" and a "monster," he was designed as a "human being" with distinctive features and capacities developed from his unique biotechnological reproductive circumstances and early child development (Shelley 2012: 14, 36, 33).

As for children's nondiscrimination rights, the tragic story of the Creature's abandonment, abuse, and neglect—due to his creation with a deformity—suggests the right of all children (GM or non-GM) to nondiscrimination on the basis of reproductive circumstances or features of genesis. We have seen that deterministic approaches to justifying children's fundamental right to love could easily lead to discrimination against GM children for their different genetic features. In addition, GM children could be made by rogue scientists, like Victor, in a cold laboratory environment, with unregulated use of gamete donors and surrogates (or, prospectively, artificial womb technology), and without parents to love and care for them upon birth (Knoepfler 2016: 208). Groups may also emerge that denounce the creation of GM children and seek to deny their civil, political, and human rights on the grounds that their DNA is different than human DNA (Knoepfler 2016: 223). There also may be systematic as well as systemic forms of social, cultural, and religious discrimination against GM children and their families that prevent their enjoyment of equal opportunities for education, healthcare, association, free speech, church membership, sports, work, property, and other civil liberties (EEOC 2008; Mehlman 2010: 71–111; Mason and Ekman 2017: 42). In a culture that puts a high price on non-GMO labels and denounces Frankenfoods as bad for kids, what would it be like to grow up as a GM child confronted with such stereotypes?

On the flip side, non-GM children of the future could suffer discrimination due to their supposedly inferior genetic features as compared to "designer" or "enhanced" GM children. There has been some speculation already that "genetically modified athletes" could have preferential status in sports if access and participation are not regulated in a way that is fair to non-GM athletes (Miah 2004). Others have argued that both GM and non-GM children may incur birth defects due to interventions of ART. These children may have disabilities that subject them to special forms of discrimination due to their reproductive origins (Smolensky 2008). Others have speculated in eugenic or evolutionary terms the inevitable destruction of the human species due to the rise of a competitor species of GM people, sometimes even called Frankenstein's monsters (Fukuyama 2002: 216; Dominy and Yeakel 2017).

Although such speculation is extreme and unverifiable in its apocalyptic assumptions about the unknowable long-term consequences of genetic engineering, its even remote possibility suggests the pressing ethical need to treat genetic features and reproductive circumstances of all children under nondiscrimination law, national and international. In order to offer truly universal coverage and protection for the most vulnerable people in society, children's nondiscrimination rights must include genetic features and reproductive circumstances alongside established nondiscrimination categories such as race, gender, and disability, plus treat these different vectors of social identity as intersecting and mutually reinforcing. As Donna Haraway powerfully imagines in her recent science fiction, the future of humanity and the environment could depend upon the flourishing—not the abolition—of genetically modified creatures, or what she calls "animal symbiont" children (Haraway 2016: 140).

From Output to Input; or, Putting the GM Child at the Heart of the Story of Genetic Engineering

The stark images of Aldous Huxley's *Brave New World* (1932) and H.G. Wells's *The Island of Doctor Moreau* (1896) have led to apocalyptic speculation about reproductive biotechnology's power to destroy human morality, freedom, or even the species itself (Fukuyama 2002: 1, 99–100). By contrast, Shelley's *Frankenstein* presents a more subtle and complex narrative about the ethics of parent-child relationships after the modification of humans through reproductive biotechnology. Read in this philosophical light, Shelley's novel emerges as a compelling resource for grappling with the ethics of parent-child relationships after three-person IVF and CRISPR-Cas9. The novel shows readers that while biotechnology may change some of the circumstances behind the parent-child relationship, including conditions of physical vulnerability and dependency (Sandel 2007: 330–331), it cannot eliminate the issue of the responsibility of parents toward the children they make.

After CRISPR-Cas9—the most efficient and cost-effective biotechnology for HGGM—it will be difficult if not impracticable to stop experimentation that crosses the human germline for either research or reproductive purposes (Gross 2016: 414). The national-level legal prohibition or halting of HGGM fails to prevent it elsewhere due to the lack of any international regulatory body to either enforce a global ban or stop scientists from crossing borders to experiment with modifying the human genome with impunity (Gross 2016: 426–437). Although issues of regulation should persist in legal reflections on HGGM, it is high time to shift the ethical focus of the debate onto the actual GM children made from tools and techniques of HGGM (Mason and Ekman 2017: 201–202).

Once GM children have been made, they can no longer be viewed as hypothetical monsters produced by a future or fictional experiment. The ethics should shift from a future concern with the GM child as a strange, even unnerving biotechnological *output* (Fukuyama 2002: 80) to a present concern with the GM child as a real, vulnerable creature with potential moral *input* (Haraway 2016: 140). What are the duties of their parents, doctors, and society toward them? What are the rights of the GM child that devolve from these duties? *Frankenstein* trains the reader's eye on these same moral and political questions, but within the framework of a gripping and many-layered story that puts the child at the heart of the issues raised by the artificial creation, modification, or transformation of (human) life through reproductive technology.

Previous bioethical readings of *Frankenstein* have focused more on the character of Victor as a scientist, less on his role as a father or parent. They have tended to privilege the medical or scientific viewpoint—the perspective of the doctor or scientist—in drawing out the novel's relevance for justifying institutional review boards for human subjects research (Harrison and Gannon 2015) and approaches to research ethics and medical ethics education (Davies 2004; Jonsen 2011). By putting the Creature's story of abandonment, neglect, and abuse at the literal center—and figurative heart—of the novel, Shelley pressed readers to take seriously a child's perspective on parental duties toward children.

However, the novel's three-tiered narrative structure makes the innermost story of the Creature known to the reader only through the scientist Victor's account of it to another would-be penetrator of the "recesses of nature," Captain Walton, whose ship is (quite symbolically) stuck in the ice of the arctic regions he sought to map for the first time (Shelley 2012: 28). The narrative frames of *Frankenstein* thus call into to question the reliability of Victor and Walton as narrators, as well as the ethics of their respective quests to achieve scientific firsts by conquering nature itself. From a medical-ethical perspective, Victor's retelling of the story of the Creature to Walton also calls into question the reliability of "narrative medicine"—both the notion of the medical provider as a "good listener" and the related notion of the "decipherable patient" (Moss 2015). Seen from this angle, Victor is not only an irresponsible parent and reckless explorer of the frontiers of medicine but also a bad listener and caregiver. The Creature is not only an artificially made and modified child but also—more to the crux of the matter—an abused pediatric patient of rogue reproductive medicine.

Conclusion: Toward the Defense of the Rights of the GM Child in Law and Healthcare

In the Shelleyan spirit of sharing "sympathies" with Frankenstein's Creature, bioethics should become more attentive to the perspectives, health, and well-being of GM children as a path toward articulation of the rights of the GM child. The 1989 Convention on the Rights of the Child (CRC) provides a promising normative framework for recognizing the rights of the GM child in national and international law. Its preamble states that each child "for the full and harmonious development of his or her personality, should grow up in a family environment, in an atmosphere of happiness, love and understanding"; Part I, Article 2 specifies nondiscrimination rights, including rights to nondiscrimination toward "disability, birth, or other status"; and Part I, Article 7 specifies rights to "a name," birth "registration," "nationality," and "as far as possible…to know and be cared for by his or her parents" (United Nations 1989). While the CRC's language could justify a child's "right to know" gamete donors or surrogates (Mason and Ekman 2017: 19, 58, 60), it also allows for further specification of more basic rights for GM and non-GM children alike: (1) children's right to share love with (biological and/or social) parents or fitting substitutes and (2) children's right to nondiscrimination on the basis of circumstances of birth, including reproductive origins and genetic features. After empathetically hearing—not just listening to—the nameless Creature's devastating story of the deprivation of love due to his biotechnologically produced deformity and other circumstances of birth, bioethicists should be moved to articulate the fundamental and universal rights of children regardless of how, by whom, or from what they were made.

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The Ethical Complexity of Using Whole-Exome Sequencing to Detect Adult-Onset Conditions in the Prenatal and Pediatric Settings

Jennifer Murphy and Jazmine Gabriel

Background: Clinical Utility of WES

Since whole-exome sequencing (WES) became available in the clinical setting, the utility of this type of testing has been well documented (Iglesias et al. 2014; Nguyen and Charlebois 2015; Yang et al. 2013). By sequencing the entirety of an individual's coding DNA, the diagnostic yield is much higher than traditional techniques such as karyotype, microarray, or sequencing a smaller selection of genes. WES yields a diagnosis in approximately 25–28% of individuals versus 3.5–10% with karyotype and 15–20% with microarray alone (Miller et al. 2010; Shaffer 2005; Shevell et al. 2003; Xue et al. 2015; Yang et al. 2013). The current standard of care is to use a stepwise approach to first rule out the most common cause of a particular disease or symptom and then reflex to the next most common cause until a diagnosis can be made. This method can be both time-consuming and expensive, and, in a large number of cases, a diagnosis may never be reached.

Having a known disease allows healthcare providers to appropriately and preventatively manage their patients based on the expected phenotype. Without a known etiology, healthcare providers are left reacting to symptoms instead of anticipating them. Knowing the natural history of a condition leads to better preparation for potential health complications. Diagnosis can also provide a measure of psychological

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relief to patients and their families because they are finally able to set their expectations and better understand the course of their disease. Otherwise, they may continue to face uncertainty and anxiety about their future.

In the prenatal setting, using a stepwise approach to diagnosis is no longer ideal for a variety of reasons. First and foremost, timeliness of results is imperative when it comes to decision-making regarding the pregnancy. The family's decision to either continue or terminate the pregnancy may be based on their test results, and their decision is time-sensitive depending on local pregnancy termination laws. The time-consuming nature of traditional reflex testing sometimes prevents the family from having a decision at all. More practically, after obtaining a chorionic villus sample or an amniocentesis sample, the fetal cells will only be viable for a few weeks, making the amount of testing available for any one sample finite.

Another important limitation of prenatal testing is the restricted clinical picture. Screening for common aneuploidies such as Down syndrome, trisomy 13, and trisomy 18 can be performed using a combination of ultrasound and blood work, with much greater accuracy than previously available. However, ultrasound alone is the primary screening tool used to detect less common genetic conditions. Generalized ultrasound findings often have a long list of potential etiologies including teratogens, infections, chromosome abnormalities, genetic conditions, multifactorial causes, or sporadic findings. Any single ultrasound finding could be associated with hundreds of genetic conditions. Ultrasound detects major birth defects, but has limited or no capability to predict developmental delays, intellectual disabilities, behavioral differences, or subtle dysmorphic features that would give healthcare providers important clues about the differential diagnosis. Without the entire clinical picture, healthcare providers are left with generalized findings, a broad differential diagnosis, and limited resources for testing.

The advent of next-generation sequencing (NGS) has mitigated some of these issues by giving healthcare providers access to larger gene panels and WES (Xue et al. 2015). NGS uses massively parallel sequencing to conduct high-throughput testing of large amounts of genomic information in a much more time- and cost-efficient manner than Sanger sequencing, which sequences one nucleotide at a time. So, while reflex testing made economic sense in the past due to the costly nature of Sanger sequencing, clinicians are now relying more and more on larger gene panels and WES. With this reliance, a number of ethical concerns have arisen. Here we focus in particular on issues related to secondary and incidental findings associated with testing.

The ACMG's Position on the Return of WES Results

While WES gives information about gene targets known to be associated with the patient's presenting phenotype, it also gives information about gene targets that are well-defined but not associated with the patient's phenotype. There is also a substantial amount of raw data, the significance of which is currently unknown, but which may become interpretable in the future. Results that are unrelated to the initial testing indication, whether they can be anticipated or not, are known as incidental findings. Secondary findings, more specifically, are incidental findings that have been intentionally sought out (PCSBI 2013).

In anticipation of a variety of logistical issues regarding counseling and returning results for WES, the American College of Medical Genetics and Genomics (ACMG) published a policy statement with points to consider, advocating clear guidelines for the disclosure of results in the clinical setting, including both those that relate to the patient's indication for testing and for secondary findings (ACMG 2012). In July 2013, ACMG made more specific recommendations regarding secondary findings by curating a list of 57 genes, representing 24 distinct conditions, for which reporting should be obligatory. Regardless of age and excluding fetal samples, all patients should receive the results of pathogenic or likely pathogenic mutations in this minimum list of genes. Emphasis was placed on choosing conditions for which treatment is available and/or preventative measures could be taken, as well as ensuring that variants of uncertain significance not be returned. The results from the minimum list should be clinically actionable (Green et al. 2013).

Two additional issues the 2013 recommendation addressed were patient preferences and reporting incidental findings in children. Initially, the Working Group suggested that patients should not have the opportunity to opt out of receiving results from genes on the minimum list. In other words, all patients undergoing the test would be required to learn specific information about their exome regardless of their preferences. This proposal was based on the selected conditions being adequately prevalent and treatable such that the laboratory's and healthcare provider's fiduciary responsibility to prevent harm would outweigh the patient's autonomy and "right not to know." The Working Group argues that as long as the ordering healthcare provider has had a thorough discussion of the risks, benefits, and limitations of WES, patients could decline testing altogether if they were sufficiently concerned about receiving a secondary finding (Green et al. 2013).

ACMG later updated their recommendation to include an opt-out option, following a report by the Presidential Commission for the Study of Bioethical Issues and results from a survey of ACMG members (ACMG 2015; PCSBI 2013; Scheuner 2015). However, the Working Group recommends that the list be treated as a whole; patients may not choose a subset of conditions for which to receive results. They argue that counseling for each condition separately to decide whether or not to include the results would be cumbersome for both the lab and the healthcare provider. Obtaining proper informed consent would become very difficult if each condition on the minimum list were treated separately (ACMG 2015).

The ACMG Working Group ultimately recommended that test results for children be treated the same as for adults, arguing that they did not wish to prohibit a group of individuals from receiving clinically valuable results. In other words, children and their parents do not have the option of opting out of receiving information about certain conditions unless they are willing to opt out of receiving secondary findings all together.

Return of Incidental and Secondary Findings in Children

A deeper look into the list of conditions raises some concern over the recommendation to return incidental findings in children. While the list includes 6 childhood-onset conditions, it also includes 15 conditions with variable onset from childhood into adulthood and 3 adult-onset conditions. The adult-onset conditions are associated with a hereditary predisposition to cancer: hereditary breast and ovarian cancer (HBOC), Lynch syndrome, and MYH-associated colorectal polyposis (Green et al. 2013). Some of the major concerns associated with returning the results of incidental and secondary findings for children include the creation of a "patient in waiting," overtreatment, negative impact on the parent-child relationship, stress of knowing genetic status (for child and parents), possible social stigma, insurance discrimination, and employer discrimination (Friedman Ross et al. 2013; Davis 1997). The major ethical concern can be framed in terms of a tension between beneficence, or the physician's obligation to benefit the patient, and the child's autonomy (or the autonomy of the future adult).

The adult-onset conditions have some characteristics that contribute to the problematic nature of testing children for them. First, the penetrance is not 100% for HBOC and Lynch syndrome. That is, individuals with pathogenic mutations in the genes responsible for these conditions do not necessarily develop cancer within their lifetime (Kohlmann and Gruber 2004; Petrucelli et al. 1998). Second, the medical management for any of the three diseases does not change until adulthood (age 20–25) unless the family history suggests otherwise (NCCN: Breast 2016a; NCCN: Colorectal 2016b).

Furthermore, even adults may choose to decline testing for cancer predisposition genes, regardless of whether healthcare providers believe the testing would benefit them. Genetic counseling is offered precisely so that adults may weigh the pros and cons of testing and make a decision based on their own values. Indeed, following genetic counseling, many adults who were originally interested in testing did not ultimately decide to test (Friedman Ross 2013). Revealing their genetic status to children denies them the opportunity to make this decision for themselves in the future. For these reasons, testing children for these conditions has generally been discouraged until they reach the age of consent (Botkin et al. 2015; Committee on Bioethics 2013; NSGC 2017). Requiring receipt of these results deprives future adults the right to make influential healthcare decisions. In other words, it violates their future autonomy, or what Joel Feinberg has called the child's "right to an open future" (Feinberg 1980).

Generally, the right to an open future is framed in terms of the limits of parental decision-making; however, in this case, healthcare providers are deciding what the parents should do for their children and denying parents the ability to make discriminating decisions about their children's medical care. The most child-centered approach is arguably to accept information about childhood-onset conditions, but forgo information about adult-onset conditions and/or disorders with incomplete penetrance. But parents must choose all or nothing, and thus lose the ability to respect their child's rights and health.

The primary goal when considering testing asymptomatic children for adult-onset conditions should be the child's medical benefit, followed by psychological benefit. Factors in support of testing include changing medical management to reduce morbidity and mortality, reducing unnecessary surveillance, and reducing anxiety and uncertainty (often in the case of adolescents). There are cases where the medical and/or psychological benefits are clear. In these cases, the parents and healthcare provider would decide that testing is in the child's best interest and that the testing should therefore be performed. Whenever possible, the children should also participate in the conversation and their assent should be elicited (ASHG and ACMG 1995; Botkin et al. 2015).

On the other hand, factors supporting the discouragement of testing include harms associated with overuse of surveillance measures and the psychological harm of creating a "patient-in-waiting" (ASHG and ACMG 1995; Botkin et al. 2015). The term "patient-in-waiting" refers to the state of prolonged ambiguity between disease and wellness for asymptomatic patients diagnosed with a medical condition (Kwon and Steiner 2011; Timmermans and Buchbinder 2010). Diagnosis of a disease before symptoms arise is becoming more common as technology improves, leading to potentially harmful consequences of unnecessary preventive interventions and the psychological burden of these additional measures (Westbrook et al. 1998).

There are a variety of ways in which an asymptomatic child may be harmed by the psychological burden of being diagnosed with a genetic condition. The diagnosis may foster a loss in self-esteem or otherwise have a negative impact on their self-image. The specter of disease may cause parents to be overly cautious or create an atmosphere of anxiety in the face of impending disease. As children mature and develop, they may make significantly different choices regarding continuing education, career, domestic partnering, and family planning (ASHG and ACMG 1995). In the case of predictive genetic testing, when it is clear that the child will develop the condition in the future, making different life choices may be in order; however, for conditions with incomplete penetrance, such as the cancer predisposition syndromes, the benefit of making different life choices is less clear.

Considering testing for adult-onset conditions in the prenatal setting adds an additional layer of ethical complexity. Generally, the same principles and concerns apply as when thinking about genetic testing in children. Unless there is a compelling reason to perform the testing immediately, prenatal genetic testing for adult-onset conditions has also historically been discouraged. Autonomy of the fetus or future child should be considered because testing takes away their right not to know the results. However, when pregnancy management would change or the parents would choose not to continue a pregnancy based on test results, parental autonomy supersedes fetal autonomy (NSGC 2014). Gaining information about genetic conditions prenatally allows parents to prepare to have a child with a genetic condition or to use the information for family planning such as making an adoption plan or pursuing in vitro fertilization with preimplantation genetic diagnosis (ASHG and ACMG 1995).

The ACMG's Reasoning

The ACMG Working Group acknowledges that there is a precedent for treating genetic testing differently in children versus adults based on issues surrounding informed consent. However, the group recommends that the minimum list be treated the same among all patients, regardless of age. Early professional statements, as well as subsequent national and international guidelines, recommend against testing minors for adult-onset conditions (Friedman Ross 2013). This ensures that children retain the ability to make certain decisions for themselves upon reaching an age of maturity. Put otherwise, this practice respects the right of children to an open future and the right of these future adults not to know certain information about their genetics (Feinberg 1980). It also respects the privacy of future adults, who may not wish their family members to know certain personal health information or who may have concerns about genetic discrimination by employers, insurance companies, or society more broadly.

Testing for genetic diseases complicates this picture in that the impact of test results extends beyond the individual to other family members. But this complexity does not negate the weight our society places on individual rights. To shift from the traditional position to one that permits the release of information about future adults to their parents and prevents parents from making discriminating judgments about their children's care would seem to require either new empirical information about the benefits and harms of this practice or powerful argumentation and novel insight about the value of altering the practice. However, the ACMG's arguments lack either quality.

For instance, the ACMG argues that stratifying results by age may place an undue burden on a laboratory's logistical infrastructure (Green et al. 2013). While straining the lab's logistical infrastructure may be of practical concern to the lab, it is not a justification for an ethical position. Many requirements for ethical and safe practices are not convenient and do not represent the path of least resistance. Furthermore, there are ways to parse the disorders such that providers would not have to explain each and every disorder on this list. For instance, the disorders could be divided into childhood-onset, adult-onset, and variable-onset disorders. These categories could be further broken down to specify incompletely penetrant disorders. Explaining these three to four concepts in order to obtain informed consent seems feasible; perhaps these concepts ought to be discussed in an informed consent regardless of options for opting out of information.

In support of treating all samples the same, regardless of age, the Working Group argues that more emphasis should be placed on a parent's ability to make decisions in their child's best interest (Green et al. 2013; Wilfond and Friedman Ross 2009). Given that the medical management for some of the conditions tested, such as the cancer predisposition syndromes, does not change until age 20–25, and given that the child may never develop cancer even in the context of a positive test result, there is little evidence of a direct clinical benefit from having these test results prior to adulthood.

The Working Group argues that, in some cases, WES may be the only opportunity for a family to obtain the results contained therein. For hereditary breast and ovarian cancer syndrome (HBOC) and Lynch syndrome, which are autosomal dominant conditions, a positive test in the child usually means that one of the parents is also positive for the familial mutation. The test results would likely have an immediate impact on the parent's medical management and could also benefit other family members. The parent may then undergo risk-reducing surgery to prevent cancer or engage in increased surveillance to detect cancer at an earlier stage. This would indirectly benefit the children by reducing morbidity and mortality in their parent (ACMG 2013; Green et al. 2013).

It is not clear that learning about parental risk for a predisposition to cancer is an appropriate reason to perform testing in a child. Curiosity about their own genetic status may cloud the parents' ability to make a decision in the best interest of their child. The ACMG argues that their position prioritizes the parents' ability to make decisions in their child's best interest at the same time that they emphasize the utility of the child's test results to the parents. The best interest standard, according to Beauchamp and Childress, concerns "the value of the life for the person who must live it, not the value the person's life has for others" (Beauchamp and Childress 2009: 140). To broaden the child's best interest to include benefiting family members, or even indirectly benefiting the child, may stretch the already imprecise concept of *best interest* too far.

Furthermore, using a child to find out the parents' genetic information is problematic from a Kantian perspective as a clear instance of using someone as means to an end. One could argue that children are not used "merely as a means" because the results could benefit the children by saving their parent. However, the combination of disrespecting the future adult's autonomy and using the child to find out information about the parent appears not to respect the dignity of the child as an end in and of itself.

Besides, there are clear clinical criteria for performing testing, so if parents are interested in learning their own genetic status, cancer genetic counseling to discuss the appropriateness of testing may be warranted. It is also important to keep in mind that not all parents and family members wish to know these results. That is, the ACMG should not assume that knowledge of these results will be viewed as exclusively beneficial to all family members. If the family history does not meet clinical criteria for testing, it is less clear what significance a positive result has. Because of the incomplete penetrance of cancer predisposition syndromes, even people with concerning family histories and a genetic mutation may never develop cancer; however, there may be even further reduced penetrance in people without a family history. This is an empirical question to be answered with research, not clinical experimentation without appropriate consent. Testing individuals who do not meet the clinical criteria for testing may result in an ambiguous situation with respect to determining appropriate medical management for families with an uncertain risk of cancer.

The Working Group offers that it is important to obtain results on these conditions, especially in the absence of a family history, because children may not then find out about their genetic status until they have developed the disease (ACMG 2013). If this is a significant concern, then the idea of population-based screening for these conditions should be taken into consideration. That is, if it is important enough to uniformly receive these results, even in the absence of a clinical indication, perhaps testing should be offered to everyone in the general population.

The Working Group asserts that return of these findings in the context of testing for another indication constitutes "opportunistic screening" and does not cause the same burden on the healthcare system as population-based screening (Green et al. 2013). However, if it is truly in the best interest of children whose families have no indication for cancer genetic testing to proceed with testing, then opportunistic screening unfairly benefits some children and not others. Since WES is expensive, the likely benefits will go to families who have good insurance and/or can afford this testing.

And if this testing is not primarily about the best interest of children, but rather about the best interests of family members, then the Kantian argument against this testing gains more force: children's need for WES is used opportunistically as an occasion for their parents to gain information without taking into consideration the wishes of the children as future adults. The ACMG concedes as much when they say that they consider this "a transitional moment in the adoption of genomic medicine where the parents of children undergoing sequencing do not have easy access to inexpensive, readily interpretable exome or genome sequencing" but that "[i]n the future, when parents might all have such access, the identification of adult-onset disease variants in their children could be restricted" (Green et al. 2013: 568). In other words, it's acceptable to use children's testing for their parents' information now, but in the future we can go back to respecting children's autonomy.

If it is possible that some parents (and/or some children) do not want information about, for instance, cancer risk, then the question of best interest is further complicated. The ACMG's goal is to benefit patients, but if the intended beneficiaries do not want what the ACMG believes they should want, then we can consider the ACMG's overriding of autonomy an instance of hard paternalism. To be fair, since parents are not given or aware of an option to opt out of receiving certain subsets of information, we cannot say what they want or don't want, or whether their wishes are being overridden in favor of what healthcare providers consider to be in their best interest. However, it is worth noting that the ACMG's values, not the parents' or children's, are dictating the meaning of *best interest* here. Particularly with respect to genetic information, and particularly because of abuses of the past, the relevant values for dictating receipt or nonreceipt of genetic information are generally the patient's values, not the values of the medical profession. While it may appear self-evident that preventing cancer is better than not preventing it, there are many instances of treatments that seem self-evidently better than nontreatment, but which patients are nonetheless permitted to refuse. Regardless of whether healthcare providers consider such decisions rational, they are generally obligated to respect the right of refusal (in patients with medical decision-making capacity).

In a position statement on a different topic (noninvasive prenatal screening), the ACMG acknowledges that "[p]atient preferences for information should play a pivotal role" in screening and that this "is in keeping with generally accepted genetic counseling tenets and respects that clinical utility may vary between patients" (Gregg et al. 2016: 1058). In the case of prenatal testing, the ACMG respects "a patient's unique value system" and "recognize[s] that this construct [value system] is not homogeneous across the United States" (Gregg et al. 2016: 1058). It would be interesting to hear the reasons why patient preferences matter in one context but not in the other, or to learn when clinical utility varies between patients and when it remains stable.

In a clarification of their recommendations, the Working Group reiterated that they only supported reporting known pathogenic variants (ACMG 2013). They did not address concerns about decreased penetrance of those pathogenic mutations. They also did not address the fact that some variants formerly classified as pathogenic or likely pathogenic have been reclassified as VUS's or as benign variants (P. Connors, BUMC 2017, Personal Communication).

Ultimately, the Working Group holds that the parent's right to know about a potentially life-threatening condition supersedes the child's right not to know about a secondary finding (Green et al. 2013). Much has been speculated about potential harm while weighing the risks and benefits of genetic testing and return of secondary findings in children and fetuses. There is some suggestion that the community has been overly cautious about the potential psychological harms of returning genetic testing results to children given lack of evidence. Perhaps the potential for harm has been overestimated, and more discretion should be given to the parents to make decisions about testing for adult-onset conditions (Botkin et al. 2015; Friedman Ross et al. 2013; Wilfond and Friedman Ross 2009). It will be many more years before we can ask adults who underwent prenatal WES what their preferences for return of secondary findings would have been. However, even with this information, the ethical complexity of the issue persists: respect for autonomy, of either present or future adults, is not about benefits and harms. Thus, if children grow up and report in surveys that they feel they have not been harmed, we will not have proved that it is appropriate to test children for adult-onset conditions.

When the ACMG justifies their reasoning by appealing to the parent's right to know about potentially life-threatening conditions, they assume that a parent either wants to know this information or that the benefit of learning it is great enough to trump a parent's (autonomy) right not to know. When the ACMG decides for parents that they ought to and will learn this information when they pursue WES for their children, they are making a paternalistic judgment that the benefit to the parents outweighs the parents' autonomy rights. Since parents do not lack capacity to make their own decisions, this constitutes *hard paternalism*, which can only be justified if a number of conditions are met.

One of the conditions is that "the patient is at risk of a significant, preventable harm" and another one is that "there is no reasonable alternative to the limitation of autonomy" (Beauchamp and Childress 2009: 216). Parents of children undergoing WES are only "at risk" of a significant, preventable harm insofar as they are members of the human species and, like all humans, could have a germline mutation that increases the risk of cancer. However, if risk to have a rare genetic mutation is sufficient to justify hard paternalism, an absurd number of interventions would seem to be justified as well. And, regarding the other condition, a reasonable alternative to deciding for parents would be to enable them to opt out of certain categories of information.

Conclusion

To conclude, the ACMG's position seems to be a departure from the recent past of allowing patient preferences to dictate whether, when, and which personal genetic information should be learned. When they state that this is a transitional moment on the way toward a time when more people have access to affordable whole-exome or whole-genome sequencing, they make a curious excuse for their position. This may suggest that their position is less an argument for a particular ethical position and more a statement of resignation to a future when genetic information is no longer treated as a highly personal matter. But the routinization of WES is by no means determined, and the assumption that because we can, we should or will, neglects much ethical thought that calls for thoughtful and public deliberation about the challenges raised by new and powerful technologies.

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Creating a Higher Breed: Transhumanism and the Prophecy of Anglo-American Eugenics

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Introduction

How we assess current calls for vigorous, or “radical” (Agar 2010, 2014), enhancement through befitting procreative choices depends in part on the plausibility of supporters’ rejecting all substantive ties between their views and earlier eugenics. When denying such connections, today’s advocates of vigorous enhancement (i.e., transhumanists) routinely emphasize that enhancement decisions would stem from individuals and families, not the state.[1] In a multipronged critique, I show the untenability of transhumanists’ denials.

When transhumanists distance themselves from eugenic history, Nazi eugenics tends to be at the fore. Reference to it does not settle the matter, however, for an investigation of links between transhumanism and Anglo-American eugenics yields important connections that span notions of human agency, views of our mental faculties, shared ethical commitments, and deleterious implications for democracy as we know it.

Transhumanists and Anglo-American eugenicists insist that human agency, channeled into scientific and technological innovation, supplant Darwinian evolution and henceforth direct human improvement. Their general lenses on the mind are similar, for the products of said agency would be used to dramatically heighten both rationality and prosociality and to weaken or, better, eliminate “antisocial” traits. Further, the two parties rely on rationales from public health. In so doing, transhumanists align themselves with a utilitarian ethical frame that is also evident

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[1] Like Hauskeller (2012: 40), I use “transhumanists” as an umbrella term for current advocates of radical enhancement, who share the pertinent commitments, whether or not they apply that term to themselves.

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in their broader defenses of the good of enhancement. Beyond an insistence by prominent figures that moral bioenhancement would be required of everyone (Persson and Savulescu 2008: 174), transhumanists' notions of well-being and harm avoidance yield a utilitarian-style obligation to enhance, particularly regarding cognition, that may be politically enforceable.

Though most transhumanists insist or presume nonetheless that liberal democracy will remain intact, the credibility of their assurance that it will not merely endure but even be furthered is challenged increasingly from within the discourse of enhancement supporters themselves. Not only do some transhumanists recognize that pursuing radical enhancement will involve movement away from liberal democracy, but several bioethicists have recently supported bioenhancement via procreative decision-making for the express purpose of augmenting societal well-being (Jefferson et al. 2014; Douglas and Devolder 2013; Elster 2011; Buchanan 2008). To embrace societal welfare as a basis for reproductive decisions is to risk subordinating personal druthers, by implication or even expressly, to social ends (Duster 2003).

Although the positions of transhumanists and Anglo-American eugenicists are not identical (for which view see Koch 2010), exploring in depth a number of writings from both periods allows one to show how close the parallels between them are on the level of ideas, including in some cases the very terms of their formulation. Knowledge of these connections casts unsettling light on transhumanists' alleged yearning to realize perennial human ideals.

The Need for a Fuller Assessment of Transhumanists' Claims About Earlier Eugenics

The following are representative illustrations of how transhumanists handle the relation of their thought to prior eugenics. In their dismissals of the very notion that common ground exists between their project and eugenic history, Nazi eugenics is often featured expressly, as when Julian Savulescu recently insisted that his vision of our enhancement "is not based on race or on the Social Darwinist values that the Nazi program was," being wedded instead to individual and familial freedom (2013: 41).

Alternatively, eugenic history is presented as unitary in the sense of covering Anglo-American and Nazi varieties. Thus, Savulescu elsewhere describes eugenics as "the movement early last century which aimed to use selective breeding to prevent degeneration of the gene pool by weeding out criminals, those with mental illness and the poor, on the false belief that these conditions were simple genetic disorders. The eugenics movement had its inglorious peak when the Nazis moved beyond sterilization to extermination of the genetically unfit" (2005: 38). Similarly, having observed that following World War II, eugenic undertakings in the USA and Germany "were rightly repudiated," Lee M. Silver demarcates "embryo selection from [those] abhorrent eugenic policies…with the claim that embryo selection would be freely employed in Western society by prospective parents who were not beholden to the will of the state. As a consequence, the use of the technology would not be associated with any restrictions on reproductive liberty" (2007: 254, 261; see further Pence 2012: 106–108).

Where both Nazi and Anglo-American eugenics are mentioned, the former is all but certain to shape one's estimation of the whole. This dominance is likely even where Nazi eugenics is merely alluded to rather than mentioned, as when transhumanist philosopher Nick Bostrom deplores "the sorry track record of socially planned attempts to improve the human gene pool.…In each case, state policies interfered with the reproductive choices of individuals. If parents had been left to make the choices for themselves, *the worst transgressions of the eugenics movement* would not have occurred" (2003a: 499, emphasis added; see also 2005a: 206; Savulescu and Kahane 2009: 282).

As Diane B. Paul observes, accounts that tether eugenics to "compulsion and jackbooted Nazis allow champions of the new technologies to sharply demarcate their projects from eugenics—to emphasize discontinuity.…Indeed, if eugenics is equated with coercion, it allows the enthusiasts to claim either that reprogenetics is not eugenics at all or that it is eugenics of a benign sort" (2007: 7).[2] This scenario, illustrated above, gives an unearned edge in plausibility to transhumanists' rejection of all substantive ties to eugenic history, which has helped thus far to limit opportunities for a fuller assessment of the relation of that history to transhumanist advocacy in terms of theoretical commitments and their practical implications. This evaluation has two facets. First, far from arising in a vacuum, Nazi eugenics was impacted by the already existent Anglo-American tradition, inaugurated by Francis Galton, who coined the term "eugenics" in 1883. When it came to law and policy, Germany singled out the USA for praise and emulation because its promulgation of laws on sterilization, immigration, and marriage contrasted with Britain's emphasis on voluntarism (Paul 1992: 669; 2007: 4; Kühl 1994: 25–26, 116n26). In fact, Germany's Sterilization Law of 1933—"the first major triumph of Nazi racial hygiene"—deliberately emulated US precedent (Proctor 1988: 7; see also Duster 2003: 141).

In 1911, sterilization laws existed in 6 states; by the end of the following decade, that number was 24 (Kevles 1995: 47, 111). In contrast, sterilization was not legal in Germany prior to 1933 (Proctor 1988: 96). German interest in American legal precedent on this topic is already documented in medical and scientific publications during the second half of the 1920s (Kühl 1994: 24). According to Stefan Kühl, the prior existence of sterilization laws in the USA helped expedite the Nazis' institution of Germany's own law within 6 months of assuming power (1994: 39); the Nazis could cite, too, earlier US research on the alleged biological transmission of "criminality" across generations in two families, the Jukes and the Kallikaks (39–40). The influence of US legal precedent in the area of sterilization outlasted World

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[2] Opponents' likening of transhumanist advocacy to Nazi eugenics may be self-serving, too (Paul 2005: 142); in sum, "both critics and enthusiasts have (disparate) interests in constructing a history that identifies eugenics with brutal coercion" (142). Addressing the point about critics, though certainly important, falls outside my purview here.

War II, for, at the war crimes tribunals, it prevented the allies from classifying Germany's sterilization law as such a crime (Proctor 1988: 117). German admiration was also directed at the USA for its legal restrictions concerning marriage and immigration, including the American Immigration Act of 1924 (173–174; Kühl 1994: 25–26).

Further, admiration of US and German practice was bidirectional; for example, ruing the fact that our Constitution precluded national legislation in areas such as marriage and sterilization, leaving them to states' discretion, American eugenicists not only took pride in US influence on Nazi policy but envied the Nazis' ability to promulgate laws for Germany entire (Kühl 1994: 39, 50). *Eugenical News*, a publication of the Eugenics Record Office in Cold Spring Harbor, New York, was a route through which awareness of eugenics was promoted in the USA during this period (Allen 1986: 245–246). In a 1937 article published there, Harry Laughlin lauded *Erbkrank*, a German film whose US distribution he facilitated (Kühl 1994: 49), for its showcasing of Germany's headway in "applied negative eugenics" (Laughlin 1937: 66). Laughlin denied that the film was racialist despite its embrace of the idea that Jews were prone to retardation and moral turpitude (66; Kühl 1994: 49). Beyond the foregoing, in the 1920s and 1930s, a web of ties existed among eugenicists in the two countries, forged and furthered by (1) correspondence, (2) publications, (3) travel, and (4) honorary degrees (for illustrations, see Davenport 1936; Allen 1986: 253; Proctor 1988: 99; Kühl 1994: 19, 59–62, 85–86; Burgers 2011: 139; Comfort 2012: 97).

The second facet of a more open and ample evaluation of how transhumanism relates to earlier eugenics is my focus here: scrutiny of the ideas and arguments of Anglo-American eugenicists shows that granting the distance of transhumanism from "the worst transgressions of the eugenics movement" (Bostrom 2003a: 499) under the Nazis is not equivalent to—and in no way supports—transhumanists' rejection of substantive ties between their views and prior eugenics as such.[3] In 1935, American eugenicist Hermann Muller stated that "[o]ur ideas of what sort of progress is possible or desirable for man must depend…upon our views of his nature" (1984 [1935]: 15). Transhumanist Gregory Stock makes essentially the same point: "At a fundamental level, [debate over human enhancement] is about… what it means to be human [and thus] our vision of the human future" (2013: 303). I will argue that transhumanists and earlier eugenicists construe this shared point in similar ways (henceforth, unless otherwise indicated, "earlier" and the like, applied to eugenics, refer specifically to the Anglo-American tradition).[4]

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[3] Though I find the relationship more concerning than she does, I concur with Paul that the true backdrop for transhumanism is Anglo-American, not Nazi, eugenics (2007: 5–6; 2005: 125–126). Bearing on the point about levels of concern, perhaps, is that Paul (2007) features transhumans (5), reserving mention of posthumans, whose capacities would fundamentally surpass ours, for a footnote (15n1). Paul's division suggests that they are detachable, with posthumans being the less directly relevant aspiration. For transhumanists themselves, however, the opposite is the case.

[4] Extensive common ground exists within the Anglo-American tradition despite movement away from the racialism of so-called mainline eugenics that Osborn illustrates (1968: 11, 104–105). Discussing Anglo-American eugenics by stage, including how far racialism was truly set aside, falls outside my purview here.

In the ensuing sections, I document six important, shared ideas. First is the notion that, for human development to continue robustly, our agency must supplant Darwinian evolution, henceforth steering what transpires ("Human Agency Creates, Then Becomes, the Divine"). Since transhumanists and prior eugenicists are deeply concerned with the capacities of future persons, they single out procreative decision-making as a key arena in which this direction should occur. According to Savulescu and Guy Kahane's (2009) Principle of Procreative Beneficence (PB), parents are morally obliged "to create children with the best chance of the best life." Or, on Muller's formulation, "[w]hen we consider what the recognition of [his favored procreative] principle would mean for…children…our obligation becomes clear and compelling" (1984 [1935]: 112).

As to the traits that science and technology would address, reason and prosociality are singled out for augmentation ("Our Elevation with Respect to 'Non-disease' Conditions"); correspondingly, our capacity for "negative," or "antisocial," emotion would be tamped down, even eliminated ("In Tandem, Eliminate the Allegedly Deleterious"). Turning to social, political, and ethical rationales, one finds argumentative recourse to the sphere of public health, where measures' justification is always utilitarian ("The Great Wingspan of Public Health"). Further, then and now, the broader ethical grounding of proposals for dramatic human improvement is often itself utilitarian. This is avowedly so for Anglo-American eugenicists, but transhumanists, too, depend on utilitarian rationales, their insistent vaunting of autonomy notwithstanding ("Shared Utilitarian Commitments"). Not only does this reliance shape measures' choice and justification, but a utilitarian perspective on human improvement has sociopolitical implications that would jeopardize our ongoing commitment to liberal democracy ("Sociopolitical Commitments and Implications").

This last point is crucial both in its own right and because the bulwark of transhumanists' defense against the contention that substantive links exist between their thought and earlier eugenics is the claim that the latter was state-managed, while their thought regarding enhancement features personal discretion (cf. Paul 2007: 8; Rubin 2014: 127–128). Absent this barrier between state steerage and personal choice, transhumanists' ultimate defense against the charge of substantive ties to prior eugenics—that decisions to (or not to) enhance would be our own—evaporates.

Human Agency Creates, Then Becomes, the Divine

Our first shared feature is the view that human agency, or "rational evolution" (Savulescu 2005: 38), should replace the Darwinian variety as the controller of our development, with species-changing results (see also Harris 2010 [2007]: 3–4). Transhumanists emphasize that natural selection is blind (Naam 2005: 232; Broderick 2013: 436; Chislenko 2013: 143) and painfully slow (Stock 2003: 184; Blackford 2010: ii). These features of it, conjoined with our increasing scientific knowledge and technological adeptness, have rendered natural selection “largely irrelevant to the larger trajectory of [our] evolution,” which, going forward, should instead be governed by “conscious design” (Stock 1993: 227–228).

This scientific-technological steerage is requisite because “[it] will grant us awesome powers…to…proactively remake Humanity.…We can transcend our original biological nature, and become *as if* divine; we’ll be as far ahead of current human capabilities as current humans exceed the prowess of our ape forebears” (Wood 2013). Embracing “the imperative to progress” (More 2013c: 267) will lead to our creating “god-like beings” (Walker 2002), or “demi-gods” (Harris 2003: 95). Indeed, vastly augmented existence “is the birth right of every creature, a right no less sacred for having been trampled upon since the beginning of time” (Bostrom 2010). That said, precisely because “[t]he transformation is profound,” posthuman experience is currently “[b]eyond dreams. Beyond imagination” (Bostrom 2010).

Such talk is far from new: Galton proclaimed that “[w]hat nature does blindly, slowly, and ruthlessly, man may do providently, quickly, and kindly” (1904; see further Brewer 1935: 124; Muller 1984 [1935]: 45; Osborn 1968: 117). The key is subjecting our development to “rational control” (Huxley 1936: 28) versus leaving it to chance (Muller 1984 [1935]: 24, 100). Reflecting this mission, work at the impactful Eugenics Record Office, established in 1910, was governed by a vision of eugenics as “the scientific management of human evolution” (Allen 1986: 264). Per Karl Pearson in “The Ethic of Freethought,” to the extent that human reason grasps the infinite and translates that apprehension into practice, “the apparently finite mind of man…rules the infinite.…[As the] master of his own reason [man is] lord of the world” (1901: 20; cf. Haldane 1932: 147). In other words, eugenics “is no longer solely an aspiration” (Osborn 1940: 293).

For prior eugenicists—like transhumanists—scientific-technological advance is not valuable intrinsically but because it will enable us to create “the superman of the future” (Haldane 1966 [1932]: 164); fittingly, Haldane named his earlier work laying out this vision *Daedalus* after the ancient sculptor whose creations were said to have powers fundamentally surpassing their original, given natures (1995 [1923]: 36–37; cf. Plato, *Meno* 97d-e [Plato 1903]). Haldane’s optimism about the future stems from his conviction that “not one of the practical advances which I have predicted is not already fore-shadowed by recent scientific work” (1995 [1923]: 46)—a confidence lavishly evinced by transhumanists now (see, e.g., Stock 1993: 158).

Further, like transhumanist philosopher Bostrom (2010), Frederick Osborn employs language of rights, claiming that “greater physical and mental perfection… should be the birthright of every human being” (1968: 111). Earlier eugenicists, too, use religious terminology: “[I]f mankind comes to realize its imperative mission to create out of itself something infinitely nobler and better…then eutelegenesis [i.e., eugenically steered procreation] will become a new evangel” (Brewer 1935: 126). Muller, in turn, exults that “miracles of transfiguration” await (1984 [1935]: 77). Unsurprisingly, transhumanists address the possibility that our successors may free themselves from earth altogether (see Stock 1993: 236; Kurzweil 2005; Moravec 1988, 1999). Muller, however, envisions that prospect, too (1984 [1935]: 62–64), and in “The Last Judgment,” Haldane presents space exploration as required for the avoidance of human extinction (1927: 287–312; see further 1932: 146–147; Esposito 2011: 42). Finally, for prior eugenicist Osborn, as per Bostrom (2010), because the divide between present and future is steep, the content and modes of future existence are “beyond [our] imagination…today” (Osborn 1968: 116). The foregoing thematic and linguistic parallels are striking, indeed.

Our Elevation with Respect to “Non-disease” Conditions

According to PB, “[a]s…our ability to…select non-disease characteristics increases…[this principle] will require most reproducers to select the most advantaged child” (Savulescu and Kahane 2009: 281). The insistence of transhumanist John Harris (2010 [2007]: 53) that “possible functioning” replace the “normal” variety in the vein of Norman Daniels (1994) points to a similar decisional requirement. Some now view CRISPR as central to PB’s fine-grained implementation, the hope being that “‘fit’ alleles would be fixed into the population with gene editing technologies. The ‘unfit’ alleles would eventually be lost.…[U]s[ing] CRISPR to decide which beneficial alleles get passed on…would allow us to bypass natural selection in totality” (Sahu 2017). As to what our agency should act *upon*, a key concern of transhumanists and past eugenicists is to dramatically heighten qualities viewed as beneficial and presumed to be such all the more once augmented. Then and now, the paramount features to be elevated are rationality/intelligence and prosociality.

Transhumanists depict their thought as anchored in the Enlightenment (Bostrom 2003b, 2005a: 202; 2005b; Pence 2012: 18; Bailey 2013: 338; More 2013b: 4, 10). Beyond displaying an allegiance to rational essentialism (More 2013b: 6), they single out reason for radical augmentation (Stock 1993: 56–60; Savulescu 2005: 38; de Grey 2013: 218; More 2013a: 450). Per Bostrom, “if what is good for us is to develop and exercise our rational nature, this implies that it would be good for us to become posthumans with appropriately enhanced cognitive capacities” (2008: 130). Once this occurs, even “today’s greatest geniuses [will] seem like simpletons” (Stock 1993: 167).

In addition, transhumanists offer dramatic comparisons across ontological planes. Though right now, “we’re just dressed-up chimpanzees” (Minsky 2013: 168), posthumans’ ability to think “will exceed human ability…by the same order of magnitude that human ability exceeds” that of chimps (Walker 2002). Beyond this, Stock foresees the emergence of “forms that transcend…human beings…by even more than we transcend the primitive worms and skeletons of the past” (1993: 52), and Hans Moravec anticipates that “disembodied superminds [will be] engaged in affairs of the future that are to human concerns as ours are to those of bacteria” (2013: 181).

For prior eugenicists, too, reason is our paramount faculty. Pearson channels Kant, a preeminent Enlightenment figure, when claiming that what matters most is “uniform obedience to rational law” (1901: 121). Because reason “is the only law-giver…[t]he only practical method of making society as a whole approach the free-thinker’s ideal of morality is to…teach it to use its reason in guiding race instincts and social impulses” (114). In keeping with this view, and like transhumanists (e.g., Harris and Holm 2002: 357, 366; Bostrom and Ord 2006; Savulescu 2013: 54), Pearson’s Enlightenment-style adulation of reason and science prompts him to dismiss opposition to his vision as irrational (1901: 430–431); J.B.S. Haldane, too, is concerned that “irrational” beliefs of non-experts will stymie scientific discoveries (1995 [1923]: 38).

In the 1930s, when “positive” eugenics came to the fore (Kevles 1995: 178), increased emphasis was placed on using reason to augment rationality itself,[5] for, compared against the heightening made possible by advancing knowledge of human genetics, existing humans are “an extremely primitive and imperfect type of rational being” (Haldane 1966 [1932]: 153–154). Further, like transhumanists, past eugenicists offer comparisons across planes of creaturely existence. Haldane observes that “[t]he change from monkey to man might well seem a change for the worse to a monkey. But it might also seem so to an angel” (1966 [1932]: 153).[6] Similarly, Herbert Brewer suggests that we are “the forerunners of beings as superior to ourselves as we are to the apes”—which possibility “gives to eugenics its most powerful inspiration” (1935: 121). Beyond this, if Muller is to be believed, we will eventually surpass mankind more dramatically than we now surpass amoebae (1984 [1935]: 124), and, per Haldane, “our descendants may…excel us a great deal more than we excel worms or jellyfish” (1932: 142).

Regarding prosociality, in several publications beginning in 2008, Ingmar Persson and Savulescu judge the “dispositions” of altruism and justice to be the core of morality, and peg our prospects for avoiding existential catastrophe through climate change and weapons of biological and nuclear varieties to the technological intensification of those traits (2008, 2012, 2013; Savulescu and Persson 2012). Earlier eugenicists, too, target prosociality, as when Huxley deems it urgent that we harness eugenics to the improvement of “social virtues” (1936: 28) and Muller contends that, apart from heightened rationality, mankind’s “adjustment to the ever more complicated situations to which he may attain in his progress will require… genetic advance…in the temperamental characteristics that make for coöperative behavior” (1984 [1935]: 37, 102), namely, “sympathy,” “benevolence,” and “altruism” (36, 49, 118; cf. Osborn 1968: 88; McMillan 2016: 106). Relatedly, Savulescu’s (2005: 37) embrace of a genetically instilled “sunny temperament” is matched by Muller’s (1984 [1935]: 69) claim that the very mission of biology is “to make us all…happy in ‘natural’ temperament.”

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[5] It was C.W. Saleeby who, with Galton’s blessing, introduced the terms “positive” and “negative” eugenics (Kevles 1995: 321n1).

[6] Haldane eventually retracted his support of positive eugenics (Paul 2005: 132, 143).

In Tandem, Eliminate the Allegedly Deleterious

Further, both transhumanists and prior eugenicists adopt a hostile lens on emotions that they view as individually and socially destructive.[7] Among transhumanists, Savulescu and Kahane target our very capacity for "negative affect" (2009: 281), as "[t]he problems of a hot temper can include life in prison" (Savulescu 2005: 37). Savulescu and Kahane presume that we would be better off "if everyone were…less aggressive" (2009: 284). Notably, the built-in harmfulness of "negative affect" is inadequately defended; for example, as in earlier eugenics, anger and aggressiveness are conflated (Savulescu and Kahane 2009: 284; Savulescu 2005: 37).

According to Haldane in 1923, science properly seeks "the subjugation of the dark and evil elements in [man's] own soul" (1995 [1923]: 46); he is optimistic that "[a]s our [biological] knowledge…increases we may be able…to control our passions by some more direct method than fasting and flagellation…to deal with perverted instincts by physiology rather than prison" (43). Muller agrees: once knowledge of the brain suffices, interventions will eliminate what is deemed deleterious from "temperaments, moods, and characters" (1984 [1935]: 72–73). A prominent concern is to minimize or, preferably, eradicate the existence of "antisocial" traits, under which is lodged "criminality"—a term of which earlier eugenicists were particularly fond, to which, however, Savulescu's (2005: 37) "[a] life in prison" is comparable (on this theme in earlier eugenics, see Haldane 1995 [1923]: 43; Davenport 1936; Mehler and Allen 1977; Allen 1986: 233, 260; Kevles 1995: 71–73, 101, 103; Comfort 2012: 101).

What is more, Haldane presages transhumanist assertions that moral bioenhancement, once available, would be mandatory to stave off existential catastrophe: "Moral progress is so difficult that I think any developments are to be welcomed which present it as the naked alternative to destruction [i.e., human extinction], no matter how horrible may be the stimulus which is necessary before man will take the moral step in question" (1995 [1923]: 47;[8] see further Esposito 2011). Or, as Persson and Savulescu formulate the point 85 years later, "[i]f safe moral enhancements are ever developed, there are strong reasons to believe that their use should be obligatory, like education or fluoride in the water.…That is, safe, effective moral enhancement would be compulsory" (2008: 174). Similarly, for Allen Buchanan, who supports enhancement, albeit not the radical variety, "[g]iven the current human propensity for violence…the human race might come to need [moral bioenhancement] interventions as part of a more complex strategy for [avoiding] catastrophic violence" (2008: 17).

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[7] Judgments of positive and negative in the realm of emotion are distinct from "positive" and "negative" eugenics; notably, positive eugenics includes the augmentation of rationality. That said, they are closely related: on the one side, the tamping down of antisocial emotions falls under negative eugenics; on the other, the heightening of fellow feeling belongs to the positive variety.

[8] Cf. Haldane's "the old paradox of freedom" (48), which he resolves in favor of doing whatever is needed for human survival.

Already in 1924, Bertrand Russell saw a program of pronounced emotional dampening as highly dangerous: either emotional capacities would be narrowly calibrated to people's societal roles or, more bluntly, the physiology of all save authorities would be modified to foster docility (Russell 1924: 53–55). Russell's point about emotional muting is well taken now to the extent that transhumanists, like prior eugenicists, collapse the distinction between aggressiveness and anger, which can be both legitimate and strong. Should we adopt transhumanists' vision of our emotional "advancement," our very capacity for anger—a powerful psychic impetus to individual and interpersonal enrichment, not to mention the amelioration of social injustice—may eventually fall away (for further criticism of transhumanist moral psychology, see Levin 2016, 2017; Jotterand and Levin 2017). But whether or not one shares Russell's concern regarding emotion, he rightly directs our attention to social, ethical, and political frames and justifications for enhancement measures.

The Great Wingspan of Public Health

Regarding those broader frames and warrants, let us observe, first, that transhumanists and earlier eugenicists draw examples and justifications from public health, where measures' ethical warrant is the welfare of society at large, that is, utilitarian. Transhumanist Andy Miah links his argument for radical enhancement with headway in public health by pointing to the salutary impact of fluoridated water (2013: 298). Similarly, Gregory Pence's rubric of "building better kids," used of a utilitarian warrant for vaccinations (2012: 135), promotes his broader goal of defusing resistance to bioenhancement, for "[w]e could be so much more than we are, if only we had the courage to pursue that vision" (186). For Sarah Chan and Harris, there is no moral distinction "between a disability and an inability from the point of view of the legitimacy of altering that state" (2006). Regarding inabilities, healthy, unvaccinated people are no different from those whose memory and concentration would benefit from augmentation inasmuch as vaccinations for the first and stimulants for the second have the same rationale (Chan and Harris 2006). In addition, "if neuroenhancement is of benefit, it may well be desirable to encourage its use. We already accept the society-wide use of other beneficial interventions, from fluoridation of drinking water to the wearing of seatbelts in motor vehicles" (Chan and Harris 2006). With equal warrant, all of these are properly called "enhancement strategies" (Chan and Harris 2006).

Public health references and rationales also figure in defenses of particular types of bioenhancements. Thus, Persson and Savulescu's argument for requiring moral enhancement to forestall existential disaster is presented as gaining traction from existing public health imperatives (2008: 174), while Bostrom pursues the link to public health apropos of cognitive augmentation (2003a). Lowering one's susceptibility to infectious disease has "positive externalit[ies]," namely, "we may…contribute more to society and consume less of publicly funded healthcare" (501).

Bostrom then uses such externalities to justify cognitive enhancement: though "political realities" do not currently allow for requirements, "[i]f…the positive externalities outweigh the negative ones, then a *prima facie* case exists not only for permitting genetic enhancements aimed at increasing intellectual ability, but for encouraging and subsidizing them too" (502).

Similarly, Buchanan references herd immunity and underappreciated economic boons of immunization to buttress his advocacy of cognitive augmentation (2008: 9–10, 29n7). His counterpart to Bostrom's positive externalities is "network effects," such that "[w]here network effect *thresholds* are present…the state may see its role as that of priming the pump, by providing subsidies, tax credits, or other incentives to encourage people to have the enhancement" (11). Neil Levy, in turn, leverages fluoridation and vaccines when arguing that cognitive enhancement could be required for its simultaneous benefit to individuals, above all, children, and society at large (2013: 38); the justification for mandatory enhancement becomes stronger to the extent that "the costs (or the forgone benefits) accrue to individuals other than the (un)enhanced person" (38). Levy advocates expressly for surpassing what obtains in the case of fluoridated water, which is hard, but not infeasible, to avoid (38). For him, requiring the use of bioenhancers that augment "general-purpose [cognitive] capacities should be no more controversial than the teaching of logic or general reasoning skills" (39).[9]

In the era of prior eugenics, it and public health were judicially entwined in Oliver Wendell Holmes' declaration in *Buck v. Bell* (1927) that "[i]t is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes." Another institutional reference point was the American Public Health Association (APHA), whose annual meeting in 1934 included a eugenics-themed exhibition (Kühl 1994: 44–45). Further, William W. Peter, secretary of the APHA, spent 6 months in Germany during 1933–1934; he was the first American eugenicist who visited that country to gather "information and evidence with which [eugenicists in the USA] could counter criticism" of Germany's eugenic measures (53–54). The linkage of eugenics and public health in earlier eugenics was no coincidence, for "[g]enetic improvement…was [seen as] the ultimate in preventive medicine" (Comfort 2012: 64), and "[n]otions of purity and perfection conditioned the minds of those interested in heredity and health" (66; for further discussion of prior eugenics and public health, see Osborn 1940: 29–37; Pernick 1997).

Though references to public health are more prominent in prior American eugenics than in transhumanism, the tie is significant there as well. And, to the extent that

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[9] Since public health measures are occupied first and foremost with prevention, it may seem odd that transhumanists draw on public health justifications regarding cognitive enhancement. This argumentative strategy fits, however, with transhumanists' denial of a legitimate conceptual distinction between treatment and enhancement (or, alternatively, per Parens' [1998: 5] threefold division, among treatment, disease prevention [e.g., vaccinations], and enhancement).

transhumanists use public health analogies and reasoning, they avail themselves of a utilitarian lens to justify vigorous enhancement that appears to be out of sync with their overall focus on autonomy.

Shared Utilitarian Commitments

Regarding ethical foundations, at first blush, there is a fundamental difference between transhumanism and Anglo-American eugenics: prior eugenicists directly embrace a utilitarian imperative to pursue humans' genetic improvement, while transhumanists typically insist that what they propose is not just compatible with but would further, or "maximiz[e]" (Sandberg 2013: 57), autonomy. Max More proclaims that transhumanists "all support personal choice in the use of self-directed technological transformations" (2013b: 13). And, when it comes to procreation, "[m]odern eugenics…gives couples a choice over what kind of child to have and enables them to have a child with the greatest opportunity for a good life" (Savulescu 2005: 38). Further, cognitive augmentation "generally has the effect of enhancing autonomy" (Schaefer et al. 2014: 130).

Today's advocates of radical enhancement must feature individual and familial discretion: otherwise, their defense against the charge of substantive ties to historical eugenics—that decisions to enhance (or not), as suitable technologies come to exist, would be our own—evaporates. That their repudiation of all such links centers on this point of contrast shows transhumanists' awareness of its central role (see, e.g., Savulescu 2013: 41–43; Silver 2007: 254–255, 261; Bostrom 2003a: 499). In what follows, I argue that once subject to critical scrutiny, this alleged bulwark gives way.

Transhumanists' use of rationales from the arena of public health, discussed in the previous section, itself already shows their willingness to invoke a utilitarian frame. Far from being an outlier, this argumentative reliance on utilitarian reasoning is also evident elsewhere. First, by Persson and Savulescu's own admission, personal druthers are moot when we consider the need for moral bioenhancement to forestall existential threats from climate change and biological or nuclear weapons—whatever the implications for our freedom (2008: 174; cf. Buchanan 2008: 17).

Second, as I argue at length elsewhere (Levin 2016), transhumanists' handling of well-being and harm avoidance anchors a moral requirement to enhance beyond that particular realm. Disease matters strictly "because it makes our children's lives worse" (Savulescu 2013: 40). Transhumanists reject the treatment-enhancement distinction because, in their view, the term "enhancement" is properly applied to any measure that elevates well-being, whatever its level of technological sophistication (Levin 2014: 3). Correspondingly, harm is construed in encompassing terms, such that whatever reduces well-being, compared with existing "technological options" at a given juncture (Bayertz 1994: 275), qualifies as such. According to PB, "[o]nce technology affords us…the power to enhance our and our children's lives, to fail to do so will be to be responsible for the consequences.…To fail to improve their physical, musical, psychological and other capacities is to harm them, *just as* it would be to harm them if we gave them a toxic substance that stunted or reduced these capacities" (Savulescu 2005: 38; emphasis added). By this logic, it is "irrational to sub-maximise" (Savulescu 2013: 54; cf. Vita-More 2013b: 76). In other words, the sole rational course is optimization, with available technologies setting the benchmark for what that involves at any particular time; the utilitarian lens that such arguments strongly imply features objective goods such as cognitive ability rather than pleasure or preferences, which are the alternative bases of utilitarian justifications (Levin 2016: 56, 59, 61–63).

The moral imperative to forestall harm, alongside the view that rationality must henceforth guide our development, is ultimately incompatible with our leaving enhancement-related decisions to individual and familial discretion. Savulescu says that "we have an obligation to try to manipulate [features such as intelligence] to give *an individual* the best opportunity of the best life" and that "[t]he critical question to ask in considering whether to alter some gene related to complex behaviour is: would the change be better for *the individual*?" (2005: 38; emphasis added). Regardless of who is choosing and on whose behalf, the rational, morally required decision will be largely or entirely the same (see also Sparrow 2011: 35). In other words, "an/the individual" here is synonymous with "each and every individual." Though Savulescu does not directly address the query as posed, his answer to the question, "Should we decide what breed of humans to create?" (2005: 37), is clearly yes—as signaled by the article's title: "New Breeds of Humans: The Moral Obligation to Enhance." *Pace* Daniel Wikler, the operative perspective on well-being does not express benign aggregation of individuals (1999: 190).[10]

Prior eugenicists openly give primacy to overall well-being. According to Muller, "[t]hrough all our visionings of progress [spearheaded by science] we must again and again remind ourselves that the object of all [our] human efforts must be to increase the sum total of the happiness of humanity" (1984 [1935]: 68). Huxley commends Muller for seeing that "[s]ocial salvation" must supplant "individual salvation," with "the social system remodelled so that individual success does not conflict with communal welfare" (Huxley 1936: 29); a key entailment of this stance is that "any sacrifice involved in parenthood" will be made with said welfare in view (29). Pearson, in turn, avows that he embraces "a truer expression of the basis of utilitarian morality" (1901: 9, cf. 308); Haldane expresses a similar view (1932: 110–111).

Earlier figures stress the entwining of ethical and political frames. Thus, for Pearson, socialism is at once "a…scheme of political change" and "a new morality…denot[ing] the subjection of all individual action to the welfare of society"

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[10] A tendency to think in general terms about what is best is also evident in the currently shifting focus from "personalized" to "precision" medicine, which (via, e.g., its statistical bent) "represent[s] a significant departure from the individualistic ethos that initially facilitated public and political support for the genomic medicine movement" (Juengst et al. 2016: 22–23).

(1901: 413). In particular, "[t]he birth of children is a responsibility, the moral gravity of which is far from being properly weighed" (419); because he saw it as conducive to a higher birth rate among those deemed more genetically fit, Pearson supported women's emancipation (418–428).

Pearson is an avowed socialist (1901: 345) since from its vision alone can scientifically based prescriptions for human improvement be issued with the force of morality behind them (323–324). Thus, when transhumanist Stock contends that the nature and trajectory of scientific and technological advance should drive both our moral obligations and the form that society takes (1993: 199–211), he is broadly echoing a view expressed by Pearson almost a century earlier. Spurred by the foregoing, which underscores that ethical and sociopolitical commitments are interlinked, let us now concentrate directly on the latter.

Sociopolitical Commitments and Implications

The problem here for Stock and other transhumanists is that the scientific direction of what transpires is inseparable from a moral obligation to fund and use enhancements for the sake of human betterment, which lends itself to sociopolitical requirements that clash with a firm allegiance to liberal democracy. Prominent earlier eugenicists welcomed this result. Per prior eugenicist Muller, scientific steerage of humanity's development is required for "happiness," centrally including that of subsequent generations (1984 [1935]: 44–45). Because "[m]ankind has a right to the best genes attainable…withholding…these gifts…would in itself be a decision, a course of action…directed against the well-being of humanity" (113). Muller makes no bones about the fact that making real headway on his scientifically steered agenda requires social reconstitution (viii, 83, 102, 108; see also Osborn 1940: 291). Muller (1984 [1935]) and Pearson (1901) endorse socialism, while Haldane (1995 [1923]: 47) and Huxley (1936: 24, 27) foresee supplanting national sovereignty, which permits legally sanctioned, variable practices, with a more encompassing sociopolitical frame.

Unlike prior eugenicists, transhumanists routinely insist that personal freedom—the crux of liberal democracy—would be not merely preserved but enriched through one's chosen augmentations (see, e.g., Vita-More 2013a: 21; Sandberg 2013: 57; Miah 2013: 299). As observed in "Human Agency Creates, Then Becomes, the Divine," the opportunity for radical enhancement is even deemed "the birth right of every creature" (Bostrom 2010). To those who worry about movement toward state control, Savulescu responds: "The best defence against a slide towards the abuse of any powerful technology is ethics," above all, "a robust respect for freedom" (2013: 43). Allegedly, it is critics of transhumanism whose "current regulations…are…[harmfully] eugenic," for "[t]hey are based on a certain vision of how the population should be…and indeed people are coerced into having children this way because they're denied the freedom to use technology and denied the knowledge that's available" (41; see also Naam 2005: 166).

One finds confidence that liberal democracy will remain intact across the broad spectrum of enhancement stances. Representing devotees of vigorous enhancement, Silver assures us that "it is individuals and couples…*not governments*…who will seize control of these new technologies" (2007: 10; italics in original); thus, recourse to reproductive technologies such as embryo selection "would not be associated with any restrictions on reproductive liberty" (261, cf. 255). Caplan et al. (1999) and Wikler (1999)—who, though not transhumanists, are generally sympathetic to enhancement—cordon off the voluntaristic focus of procreative choices now from past instances of force and coercion (Caplan et al. 1999: 1284; Wikler 1999: 191). And Bill McKibben, a bioconservative, takes for granted that, going forward, enhancement will be a matter of "mere consumer decisions" (2003: 37). Even Daniel Kevles, well known for his classic history of earlier eugenics (Kevles 1995), fails to see the aforementioned sociopolitical danger. What concerns him instead is that "eugenics…could come back, only in a new, private form shaped by the dynamics of democratic consumer culture. What could happen now is likely to be far more bottom-up than top-down…individuals and families choosing to edit their genes…and finding themselves encouraged to do so by what was absent in the era of eugenics: the biotechnology industry" (Kevles 2015).

As one might expect, today's critics of radical enhancement also voice worries about the continuance of liberal democracy (see, e.g., Sparrow 2014a, 2014b; Vallor 2011: 148). Strikingly, however, the credibility of transhumanists' insistence that democracy as we know it will remain intact is increasingly challenged from within the discourse of enhancement supporters themselves. There are two camps here: one recognizes that the pursuit of vigorous enhancement will involve movement away from liberal democracy as we know it, while the other sees the enhancement enterprise—including state implementation—as an engine of democracy's preservation. Concerning the first, like prior eugenicists Haldane and Huxley, Persson and Savulescu (2012: 102) would like to see the framework of nation-states yield primacy to "a *global(ly* responsible) liberalism," while Stock (1993: 22–23, 96) lauds supranational Metaman as nation-states' civilizational successor (cf. Ascott 2013: 444). According to David Wood, "we'll need to accelerate a reformation of the political and economic environment, so that the outcomes that are rationally best are pursued" (2013; see also the "Transhumanist Declaration" [More and Vita-More 2013: 54]). James Hughes submits that "radical longevity and cognitive enhancement will push liberal democratic society to adopt post-liberal individualist moral, legal, and political frameworks that do not assume personal identity.…The erosion [of personal identity] *may* come about without any coercion" (2013: 231; emphasis added). Sociopolitically, "global governance is the next step" (Hughes 2004: 264). Harris, in turn, foresees legal requirements on immortality pursuers, possibly including not merely taxation but sterilization (2003: 75) and "generational cleansing," if generational succession "prove[s] too slow for regeneration of youth and ideas" (77).

Representing the second camp, Jefferson et al. argue that "[w]e should…*reframe* the debate about biomedical enhancement by giving serious consideration to the social benefits that enhancement might have" (2014: 503, italics in original). While Buchanan (2008) concentrates on societal boons from elevated productivity, Jefferson et al. advocate for using enhancements to "improve the functioning of our political communities" (2014: 502). In particular, reinvigorating liberal democracy for the sake of its long-term endurance requires a heightening of civic virtue (503); note the similarity here to Osborn's view that eugenics and democracy "are significantly interrelated" such that "[a] eugenic form of society…seems essential to the perpetuation of democracy [itself]" (Osborn 1940: 297, 299).

For Jefferson et al., individuals have a utilitarian basis for "engag[ing] in (or provid[ing] to their children)…enhancements…that…contribute to civic virtue" (2014: 525). As civic virtue is above all a function of cognitive ability (521), opting against cognitive enhancement would be not only irrational but subject to moral critique (523-524n72). What is more, the fact that "increased civic virtue is a social good…that is needed in modern liberal democracies" (526) can "alter the moral status of undertaking [pertinent] enhancements…from being merely permissible to obligatory" (525). In further keeping with utilitarian thought, Jefferson et al. give prominence to science as the arbiter of what specific measures may be morally required (525; on this feature of utilitarianism, see Smart 1973: 47; Williams 1973: 139).

Jefferson et al.'s (2014) notion that the state may override autonomy, even where individuals pose no danger that, under liberal democracy, warrants intervention (e.g., not voting or attending city council meetings), is relevantly similar to Persson and Savulescu's warrant for requiring moral bioenhancement of everyone, including—to avoid humanity's destruction due to climate change—those whose "crime" may be nothing more than, say, refusing to carpool or declining to install solar panels (2008, 2012, 2013; Savulescu and Persson 2012). Implementing mandatory enhancement measures per Jefferson et al. and Persson and Savulescu would necessitate a suspension of freedom, allegedly to secure democratic freedom itself down the line. As Harris points out (2011, 2016), we are rightly alarmed, not sanguine, in the face of this anti-democratic prospect, notwithstanding the fact that the proffered justification is democracy's own ultimate preservation.

Although only the former camp of enhancement supporters treated above departs overtly from liberal democracy, the two groups are united by a direct recognition that significant sociopolitical impacts are built into the implementation of their visions. Further, the approach of the latter camp is potentially more damaging for the temptation it represents to act on the visceral appeal of a no-holds-barred commitment to the long-term preservation of liberal democracy without proper attention to the fact that a supposed moratorium on hard-won freedoms is likely never to be just that. In sum, although the improbability of one's both giving top priority to a scientific vision of the good and steadfastly embracing liberal democracy was more starkly evident in Anglo-American eugenics, it is also manifest in transhumanist thought.

Conclusion

Nathaniel Comfort argues that “the eugenic impulse…is timeless,” not historically localizable in our American past (2012: xi). In particular, this impulse “arises whenever the humanitarian desire for happiness and social improvement combines with an emphasis on heredity as the essence of human nature. It is the dream of control, of engineering ourselves, of not leaving our future up to cruel fate” (246).

Though I concur that, seen through the lens of their shared “eugenic impulse,” current eugenics is “less benign than the public relations campaigns would have us believe” (2012: xii), I cannot agree that, due to this common terrain, earlier American eugenics (Comfort’s own focus) should come off less badly than it otherwise would (xii). The fact that we find a number of important parallels is concerning, whichever direction we approach them from. By featuring this common ground, the present inquiry underscores the endurance of contentious and problematic views about human nature, aspiration, and our flourishing that many parties in today’s debate over enhancement—whatever their stance on the radical variety—assume we have left behind. What is more, knowing these links casts new, unsettling light on transhumanists’ alleged yearning to realize perennial human ideals (Bostrom 2003b: 38; 2005b; Stock 2003: 2; Vita-More 2013b: 78). Not only do the shared commitments of transhumanism and earlier eugenics converge in Savulescu and Kahane’s Principle of Procreative Beneficence, but its powerful implications for decision-making and resource allocation in the reproductive sphere are glimpsed most clearly when one views PB as the product of a shared “eugenic impulse” reaching back to Francis Galton.

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Part II

Exploring Infertility and the Right to Reproduce

One Is the Loneliest Number: How the WHO's Redefinition of Infertility Provokes Contestations of the Body and the Body Politic

Nicholas R. Brown

Introduction

The argument I wish to advance in this presentation is a simple and straightforward one, yet one I also suspect will invite no small share of skepticism and perhaps even vigorous contestation when subjected to further examination.

In its most succinct and compact compass, my argument is this: the recent decision by the World Health Organization (WHO) to (re)define single people unable to find consenting sexual partners as both infertile and disabled and thus as eligible to receive publically financed artificial reproductive treatments commits two significant errors—one conceptual and the other normative.

Conceptually this definition ignores an intrinsic quality of disability or what Christopher Riddle (2013: 23–40) has rightly referred to as its ontological reality. For while it is certainly true that singleness as a result of unsuccessful sexual coupling invariably renders one physically incapable of reproducing, it is just as true that a proper account of reproductive disability must look beyond a mere inventory of contributing social factors, lest the meaning of reproductive disability be reduced to an exclusive focus on functional limitations. It is thus imperative to recognize that a person unable to reproduce because of unsuccessful sexual coupling is fundamentally different from a person unable to reproduce because of an underlying physiological/biological impediment and that this difference is not merely one of degree but of kind.

Normatively speaking the WHO decision rightly attends to the fact that the capacity to become a parent need not be predicated upon successful and sustained coupling. Nevertheless, it fails to see that the political practice of being a parent is invariably communal in nature and thus an enterprise whose full normative import cannot be adequately realized, let alone discharged, within the exclusive domain of

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exercising an autonomous agent's right. Indeed as Brian Duff has argued in *The Parent as Citizen: A Democratic Dilemma*, if the true goal of a flourishing public order, particularly a liberal democratic one, is not simply the establishment and preservation of a regime of rights but also the "creation of and caring for new members who will carry that tribe into the future," then it follows that the "[c]aring for our children provides the fundamental basis upon which liberal citizenship might be built and extended outward by extending parental sympathies" (2010: 133). Hence while the decision to become a parent may be solitary, the actual practice and lived experience of parenthood is anything but.

Thus taken together, these conceptual and normative errors ultimately erode the integrity of both disability and parenthood. Stated differently and by way of analogy, we can say that just as defining singleness as an infertile disability undermines the latter's conceptual integrity, so too does redefining parenthood as the exercise of autonomous right render it incapable of producing the kind of moral and political goods integral to a flourishing liberal democratic society. I will thus use the remainder of this paper to further flesh out and defend each of these claims.

Before I do so, however, it will be instructive to return to the WHO decision in question in order to further delve into its specifics as well as explore the philosophical and normative assumptions upon which it rests. In so doing, we shall be able to discern not only the *how* of this decision but also more importantly its *why*. That is to say we shall come to see that the WHO's decision to expand the definition of reproductive disability to include singlehood is not a departure nor even an aberration of modern reproductive ethics, but rather its logical, indeed its inevitable, conclusion insofar as parenthood is conceived—so to speak—as a natural liberty right.

Singleness, Infertility, Disability, and the WHO

If one were to consult the WHO's definition of "infertility" prior to October of 2016, one would encounter a complex and multivariate statement. To wit, according to the WHO's website, infertility can simultaneously be defined within three distinct categories—clinically, demographically, and epidemiologically. Clinically infertility is "a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse" (WHO 2017b: 1).[1] Demographically infertility is an "inability to become pregnant with a live birth, within five years of exposure based upon a consistent union status, lack of contraceptive use, non-lactating and maintaining a desire for a child" (WHO 2017b: 2). Lastly, the epidemiological definition holds that infertility occurs when

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[1] "Infertility definitions and terminology," *World Health Organization*, accessed April 5 2017, http://www.who.int/reproductivehealth/topics/infertility/definitions/en/. A second clinical definition of infertility is offered which states, in part, that infertility is "the inability of a sexually active, non-contracepting couple to achieve pregnancy in one year."

"[w]omen of reproductive age (15–49 years) at risk of becoming pregnant (not pregnant, sexually active, not using contraception and not lactating) who report trying unsuccessfully for a pregnancy for two years or more" (WHO 2017b: 3).

In addition to these various definitions, the WHO also classifies infertility as a disability. More specifically it states that "[i]nfertility generates disability (an impairment of function), and thus access to health care falls under the Convention on the Rights of Persons with Disability" (WHO 2017b: 4).

The WHO's definition of "disability" is itself similarly complex and multifaceted. "Disabilities," it states, "is an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations" (WHO 2017b: 1).

Furthermore the WHO asserts that disability "is not just a health problem." Rather, it should be viewed as "a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives." Accordingly "the difficulties faced by people with disabilities require interventions to remove environmental and social barriers" (WHO 2017a: 2).

What is noteworthy about both these definitions is the degree to which the WHO sees both infertility and disability as pluriform. That is, both infertility and disability are regarded as complex phenomena whose etiology owes to an intricate interface and synthesis of exogenic and endogenic factors. So while disability can be manifested on account of an immediate physical impairment, it can also be manifested because of the social exclusion and isolation that impairment causes.[2] In the same vein, infertility can be a function of disease, age, and/or sexual activity or some combination thereof. Thus to reduce infertility or disability to any one set of factors at the exclusion of others is to misapprehend their true essence.

As a short but necessary digression, though certainly not a tangential one, it should be noted that while these WHO definitions of infertility and disability demonstrate a concerted effort to preserve their complexity and polygonal nature and etiology, both nevertheless suffuse their meaning with a subtle but noticeable negative valence. That is to say, by viewing infertility as a disability, the WHO is not only providing a descriptive claim but a normative one as well, namely, that infertility is a malady in need of remediation. Such a claim is not without considerable contestation, however, especially as feminist bioethicists have critically deconstructed some of the essentialist and pronatalist presuppositions and discourses that tend to underpin its normative ambit (Parry 2005). Thus, aside from assessing the content of the definitions themselves, one could question upon what normative and political basis the WHO arrogates unto itself the authority to deem infertility as

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[2] This view is consistent with Barbara Altman's assertion that because "disability is a complex social phenomenon," it is therefore "undefinable empirically unless one reduces the focus of the definition to a specific aspect of experience" (117). "Disability Definitions, Models, Classification Schemes, and Applications" in *Handbook of Disability Studies*, eds. Gary Albrect, Katherine Seelman, and Michael Bury (Thousand Oaks: Sage Publications, 2001), 97–117.

disability. While certainly an important and essential question to be asked and explored, it is nonetheless one that falls outside the scope of my ability to adequately address within the confines of this paper. I simply raise it here to illustrate just how complex the nature and relationship between infertility and disability is, even more so than the already complex definitions of the WHO allow for.

Even so given this sensitivity to wanting preserve their complexity and multidimensionality, it should come as little surprise then that the WHO would maintain a certain vigilance in adapting or modifying their definitions of infertility or disability less some heretofore undiscovered or unacknowledged aspect get overlooked and omitted. And so it was that the WHO's international committee on assisted reproductive technology announced in October of 2016 that it would change the WHO's previous definitions of infertility and disability to now include single women and men who are unable to have children not solely because of a medical condition but also because of the "inability to find a suitable sexual partner or the lack of [a] sexual relationship which could achieve conception" (Bodkin 2016). As such, under these new definitions, the WHO would deem single men and women as equally infertile and disabled as gay and lesbian couples or heterosexual couples unable to conceive a child because of a medical condition and thus as equally deserving of publicly funded IVF treatments.

Once again, in the same vein as my discussion of the contestation surrounding the implicit negative normative evaluation of infertility above, it should also be observed how this new definition seemingly conflates the infertility of a heterosexual couple or single person with the infertility of a homosexual couple or gay person and views both as equally disabled. However, this conflation glosses over and obscures an important distinction that has comparably weighty normative import. For while it may be said that the infertility of a heterosexual couple of single person is derivate of an "abnormal" functioning of their reproductive capacities, the infertility experienced by homosexual couple or single person is decidedly quite "normal." In fact, it would be extraordinarily "abnormal" in the case of the homosexual couple at least if they did not experience infertility. Thus we arrive at a similar conclusion as we did above with the WHO labeling infertility as a disability except in this instance it is homosexuality itself that is effectively viewed as a disability. Of course such a view, even if unwittingly assumed, has to be just fiercely contested.

Be that as it may, neither the subtle reinforcement of a pronatalist discourse nor the implicit reification of heteronormativity was what elicited and drove the main outcries of criticism over the WHO's decision to redefine infertility and disability as inclusive of non-coupling singles. Gareth Johnson, a member of the British Parliament and a former chair of the All Parliamentary Group on Infertility, expressed subdued skepticism by stating "I'm in general a supporter of IVF. But I've never regarded infertility as a disability or a disease but rather a medical matter. I'm the first to say you should have more availability of IVF to infertile couples but we need to ensure this whole subject retains credibility" (Bodkin 2016). Josephine Quintavalle, on the other hand, speaking on behalf of Comment on Reproductive Ethics or CORE—a British public interest bioethics organization—registered a decidedly greater level of pique. "This absurd nonsense," Quintavalle stated, "is not simply re-defining infertility but completely side-lining the biological process and significance of natural intercourse between a man and a woman. How long before babies are created and grown on request completely in the lab?"(Perring 2016).

Yet to think these definitional changes effected by the WHO were either a case of blinkered thinking or worse a sinister pretext for legitimizing ectogenesis would overlook their true philosophical and ethical provenance—a provenance that forms the very foundation of much of modern reproductive medicine, namely, the right to reproduce. Indeed as Dr. David Adamson, one of the authors behind the changes in definitions, stated in their defense, "[t]he definition of infertility is now written in such a way that it includes the rights of all individuals to have a family, and that includes single men, single women, gay men, gay women. It puts a stake in the ground and says an individual's got a right to reproduce whether or not they have a partner" (Bodkin 2016).

Adamson's point on how redefining infertility to include uncoupled single men and women is coeval with a right to reproduce tracks closely with John Robertson's conception of procreative liberty. The liberty to procreate, argues Robertson (1994), is the "freedom to decide whether or not to have offspring." Thus "to deny procreative choice," Robertson concludes, "is to deny or impose a crucial self-defining experience, thus denying persons respect and dignity at the most basic level." As Muireann Quigley (2010) rightly observes, in this particular articulation of reproductive liberty, the right to reproduce is conceived as a negative right, that is, a right "against the interference of other individuals (or the State) in one's reproductive decisions." As such when interpreted in its broadest possible terms, it is a "right to non-coital collaborative reproduction, such as involved in the process of gamete donation and surrogacy" (2010).

Thus, as Adamson contends above, there is a logical trajectory that naturally extends the right to reproduce to uncoupled singles. For inasmuch as uncoupled singles have the same decisional capacity to choose to have a family as heterosexual and homosexual couples, then they also possess the same liberty and right to reproduce and become parents. To deny them this right, and thus the material means by which this right can be properly exercised, simply because they are uncoupled would be just as arbitrary and unjust as depriving a medically infertile heterosexual couples or homosexual couples of their reproductive rights on account of the vicissitudes of biology or sexual orientation.

The Integrity of Disability and Parenthood

Does, however, the unfettered choice to simply reproduce—whether one is single or not—adequately capture the reality of what it means to be a parent? That, of course, is a question of description. However, since this is an occasion to reflect on the ethics of reproductive medicine, there is also the prescriptive question, i.e., is this what parenthood *should* mean?

I would like to probe these questions further and make the case that parenthood so conceived, that is, as purely a negative right of reproductive freedom, does not do justice to the lived experience of parenthood either descriptively or prescriptively.

Before I do so though, I would first like to address the conceptual question of whether being an uncoupled single makes one infertile and disabled. Let us return once again to the WHO's definition of disability cited above. In keeping with its operating premise that disability is a complex and multifaceted phenomenon that encompasses physical impairments, activity limitations, and participation restrictions, the WHO maintains that disability reflects "the *interaction between* features of a person's body and features of the society in which he or she lives [emphasis added]" (WHO 2017a: 1). It bears repeating here that the WHO views the phenomenology of disability as intersectional. That is say to be disabled is *both* to possess a physical impairment *and* to endure social isolation and exclusion as result of that impairment. Neither aspect in and of itself is sufficient to be disabled although both are certainly necessary.

The problem therefore with defining uncoupled singles as suffering from an infertility disability is that it decouples the physical from the social. In other words this redefinition of disability ironically severs the very kind of symbiotic interaction between "a person's body and the features of the society in which he or she lives" that the WHO originally argues is integral to maintain. And it does so because like the social model theory of disability, there is a failure to acknowledge what Christopher Riddle calls the ontological reality of disability.

As Riddle explains a proponent of the social model theory would "view the disabling barriers in one's life as resulting from social organization, and not from individual limitations in functioning" (Riddle 2013: 24–25). Thus as Michael Oliver (1996), a leading social model theorist, writes:

> It is not individual limitations, of whatever kind, which are the causes of the problem, but society's failure to provide appropriate services and adequately ensure the needs of disabled people are fully taken into account in its social organization.

To be sure, to be disabled is to know all too well the myriad and sundry ways society deprives one of full social recognition and integration. Nevertheless, what social model theorists of disability tend to ignore or even reject, according to Riddle, is the causal link between physical impairment and social depravation. Hence, by rejecting "the argument that there is a causal connection between impairment and disability," the social model "clos[es] the door on the possibility that impairment is bad in-and-of-itself" (Riddle 2013: 26). And in so doing, "the social model does little to address the experience of pain (or welfare deficiency), and tends only to the functional limitations (or resource deficiency)" (Riddle 2013: 29).

In light of this conceptual lacuna in the social model theory, Riddle proposes that a definition of disability must also include the metaphysical or ontological reality of being disabled as well. For while "social circumstances can exacerbate or minimize the effects of impairment," the physical impairment of disability "can negatively impact well-being" as well "even in the complete absence of the effects of social arrangements" (Riddle 2013: 35).

Thus by juxtaposing Riddle's critique of the social model theory of disability with the WHO's redefinition of infertile disability to extend to uncoupled singles, we can see that it is susceptible to the same kind of fallacy and critique. That is, the WHO's redefinition ignores or even rejects the causal connection between physical impairment and social deprivation. An uncoupled single woman and a woman suffering from premature ovarian failure may both be functionally infertile and thus suffer from the same kind of social stigma and isolation that comes with being single and childless. But to maintain that both are equally disabled would be akin to saying that a man who is only a 20% free-throw shooter is just as disabled as a man who is a quadriplegic insofar as both are functionally prohibited from becoming professional basketball players. In both instances the corporeal or metaphysical dimension of disability is denied.

Analogously we can say that to reduce the reality of parenthood to the pure exercise of individual autonomy—i.e., purely as a negative right to reproductive freedom—is similarly harmful to preserving the integrity of the body politic. This is so two ways.

The first concerns a proper conception of not only of rights more generally but also of the right of reproduction in particular. While it is undeniably the case that the provision, enactment, and protection of negative rights—that is, rights whose chief aim is to secure and protect an individual's autonomy from interference—are an integral prerequisite to a flourishing liberal democracy, it is just as undeniable that the exercising of these kinds of rights alone is insufficient to that project, indeed to autonomy itself. For as Cathleen Kaveny argues, "[p]ositive freedom—autonomy—is not merely the capacity to choose, willy-nilly what one want to do here and now. It is also and more fundamentally the capacity to commit oneself to an overarching project that will take years to realize, with each new each new step building upon the last…It is impossible to preserve a political community committed to autonomy unless that commitment is collectively passed down from generation to generation" (Kaveny 2012). Thus the endurance and vitality of a liberal democratic order is just as dependent upon the provision, enactment, and protection of positive rights—that is, rights whose chief aim is to ensure the provision of certain goods and services—as it is on the exercise of negative rights.

If this securing of both negative *and* positive rights is integral to the maintenance and flourishing of a liberal democracy, then how much more so is to maintenance and flourishing of parenthood? To be sure there is a vital and essential component of parenthood that entails a significant notion of negative rights, that is, the freedom to choose whether when and how one becomes a parent or whether one becomes a parent at all and to not have the freedom infringed upon. Such a negative right has been clearly enunciated and codified in American jurisprudence. Yet as Tamar Ezer observes, American jurisprudence has also revealed, although to not as great an extent, the existence of a positive right to parenthood as well. More specifically, it views "the work of parenthood [as] both a right and a duty, endowed with special public value" (Ezer 2014). To be a parent then not only means that I have the negative right to choose to become a parent, but also the recognition that I am now simultaneously the object of the claim of another's positive right, namely, the child whose parent I have chosen to become. Thus, in a sense, I am only truly a parent to the extent that I recognize that my negative right to reproductive freedom is inextricably linked to assuming my child's right to dignity and care. Indeed, the former right is quite literally a dependent. As Ezer explains:

> Recognizing positive rights for children need not undermine either the rights of parents or those of society. Children's rights do not threaten parent's rights, but, in fact underpin them. Parent's rights are empty and meaningless when divorced from the needs of children. Children's rights do not create conflict, but rather translate existing tensions, forcing us to wrestle with openly difficult questions. Not only do positive rights for children not create conflict, but to the contrary, the affirm connections to the community. Bound up with duties and responsibilities between the state and the individuals, rather than contributing to dissolution, they strengthen connections.

Ezer's concluding point about how the positive rights of children strengthens rather than weakens communal bonds speaks to the second way a purely negative right to reproductive freedom can undermine the integrity of the body politic. For while reproduction is essential to becoming a parent, the actual practice of parenthood is, by its very nature, an inherently communal enterprise. This is the case whether one is a single parent or co-parenting. In fact, it is especially the case if one is a single parent. It is precisely because a child has a positive to right to care and dignity that a parent or parents must forge the kind of connections and relationships with not only other parents but by extension all members of their society to ensure that they have access to the necessary communal goods and institutions which make such care and dignity possible. Hence I can no more choose to become a parent in isolation from my child than can I choose to parent in isolation from my community. To pretend otherwise is to deny ourselves of the very moral and communal goods that make parenting a meaningful and worthwhile endeavor.

As such to become a parent is to incur obligations of caring, nurturing, and responsibility that one does not necessarily get to choose. Indeed, there is a great irony in linking parenthood as with a negative liberty right since the actual fulfillment of that right acts as its own negation at the same time. I may well say that I can fulfill my right to become a parent simply by exercising my right to reproduce and leave it at that. In such a situation, there can exist a mother and/or a father of a child. Yet it would be difficult to say that either or both were parents as we have come to think of and define that term short of one or both fundamentally limiting their autonomy. To be a parent then is not only to possess the freedom and right to have a child but also to forego that very same right and freedom such that the child has you. Such a practice and politic is all the more necessary and salutary in a society and culture where one indeed is the loneliest number.

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Expanding the Clinical Definition of Infertility to Include Socially Infertile Individuals and Couples

Weei Lo and Lisa Campo-Engelstein

Introduction

The Centers for Disease Control currently defines infertility as “not being able to get pregnant (conceive) after one year (or longer) of unprotected sex” (CDC 2017). “Unprotected sex” here refers exclusively to vaginal-penile intercourse. This definition is widely used in the medical literature and is used as the clinical definition of infertility by professional medical organizations like the American Society of Reproductive Medicine (ASRM); ASRM defines infertility as “the inability to achieve pregnancy after one year of unprotected intercourse” (ASRM 2012). Yet, this clinical definition of infertility excludes people not in heterosexual, cisgender couples. This means that heterosexual single cisgender individuals and lesbian, gay, bisexual, transgender, and queer (LGBTQ) individuals and couples are technically not able to be diagnosed and treated as infertile due to their relationship status. Infertility due to relationship status is known as relational infertility or social infertility (Murphy 1999) and can be contrasted with physiological infertility, which is infertility due to a medical condition (e.g., low sperm count, blocked fallopian tube). Individuals can have both social infertility and physiological infertility. For example, a lesbian woman can be socially infertile because she is in a same sex relationship but also physiologically infertile due to endometriosis.

In this paper, we argue to expand the definition of clinical infertility because the current definition is discriminatory, creating unequal access to ART and preventing insurance coverage of assisted reproductive technology (ART) for people not in

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heterosexual, cisgender couples. Others have argued that relational infertility should be recognized as its own diagnosis (Rank 2010). We instead argue for an expansion of the current clinical definition of infertility to treat socially infertile people equally, rather than creating separate categories of infertility that may perpetuate stigma and barriers to healthcare. Specifically, we focus our discussion on how the clinical definition of infertility is interpreted and applied by infertility specialists and insurance companies in the United States. We will limit our discussion to single cisgender women and cisgender lesbian couples. Single men, gay male couples, and transgender individuals without internal female reproductive organs require the assistance of a gestational surrogate, which is not currently covered by infertility mandate of any state and is thus beyond the scope of this essay.[1] Furthermore, a lesbian couple consisting of a transgender woman and a cisgender woman may be able to use sperm from the transgender woman, which may not require medical intervention.

Discriminatory Definition of Infertility

One major problem with the current clinical definition of infertility is that it automatically excludes anyone not engaging in vaginal-penile intercourse from being diagnosed as infertile. While heterosexual intercourse is the most common way people become pregnant and the failure to achieve a pregnancy through heterosexual intercourse can be an indicator of infertility, there are various medical technologies that can also demonstrate infertility in the absence of heterosexual intercourse. For example, healthcare professionals can test patients' hormonal levels and the quality and quantity of gametes in order to make a diagnosis of infertility. Yet, the definition of infertility requires patients to partake in a *specific* type of sexual activity—i.e., vaginal-penile intercourse—in order to make a diagnosis. The requirement to engage in heterosexual intercourse for the sole purpose of proving a medical diagnosis is discriminatory toward single, heterosexual women and lesbian women and couples. People's participation in a specific action that violates their personal beliefs and/or identity should not be mandatory for any medical diagnosis or treatment when alternative diagnostic tools and treatments exist. The heteronormative bias of this definition of infertility assumes that reproduction only occurs via vaginal-penile intercourse, thereby excluding single women and lesbians from consideration.

Although LGBTQ or single cisgender people are not forced to engage in vaginal-penile intercourse to establish infertility, the criterion of vaginal-penile intercourse has the de facto effect of excluding this population. For many individuals who have a strong desire for gestating genetically related children, especially those who live

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[1] Although we will not discuss the ethical issues surrounding surrogacy, it is important to note that heterosexual couples who meet the current clinical definition of infertility may also benefit from surrogacy coverage. For instance, a woman who underwent a hysterectomy due to endometrial carcinoma may wish to start a family after she is cancer free. Even if she has the foresight, opportunity, and means to preserve her eggs, she cannot carry a pregnancy due to her surgery and will need to seek the assistance of a surrogate.

in states with limited ART access for people not in heterosexual relationships, the only way to conceive may be to engage in vaginal-penile intercourse. The strong desire for gestational and genetic parenthood may lead people to make choices they would not otherwise make if they had more options, including entering mixed-orientation relationship, when two partners have different sexual orientations (Clemons 2016; Tatlow 2015). In countries that criminalize homosexuality, refuse to recognize same-sex marriage, and have sparse ART access, a heterosexual relationship (i.e., vaginal-penile intercourse) remains the only plausible and legal method for their citizens to conceive a child. China is one such an example, where 80% of, or 16 million, gay men marry women to conceive children and/or fulfill cultural expectations. Although there is less data on lesbian women entering marriage with men for the same reason, it is a known practice in the LGBTQ community in China (Davison 2011; Tatlow 2015). Without plausible options to access ART, partly perpetuated by the discriminatory definition of infertility, people across the globe may engage in unwanted vaginal-penile intercourse to become genetic parents.

Some critics may argue that engaging in heterosexual intercourse is not an unfair demand because being single or lesbian is a “lifestyle” choice and women could just as easily choose to participate in vaginal-penile intercourse. This criticism is often based in religious or philosophical objections to homosexuality and “nontraditional” gender norms, rather than grounded in empirical data. The American Psychological Association asserts that most people have little or no sense of choice about their sexual orientation (APA 2008). Likewise, single heterosexual woman may not be able to find a suitable male partner, which has contributed to the burgeoning egg freezing market as a way to anticipate and prevent age-related infertility (Hodes-Wertz et al. 2013). Even if we were to grant these critics, their objection that being single or lesbian is a choice, this in no way justifies requiring people to engage in unwanted sexual activity to establish a medical diagnosis when other options exist. The objection that women can “choose” to engage in heterosexual intercourse is simply a way of affirming the heteronormative belief that reproduction should be limited to heterosexual couples and should exclude single women and lesbian couples.

We recommend changing the clinical definition of infertility to “a condition of an individual with intent of parenthood but unable to produce conception due to social or physiological limitations within a period of twelve months.” This expanded definition of infertility will push the medical community to recognize social infertility as a clinical diagnosis that is treatable with many of the same options already available for physiological infertility. Broadening the term will also inform and encourage the policy makers and insurance companies to cover social infertility under existing infertility insurance mandates.

Since the current clinical definition of infertility depends on heterosexual intercourse, it assumes that the only cause of infertility is physiological. Individuals with physiological infertility have reduced fertility due to factors indicated by physiological causes. Examples of physiological infertility could include a woman with chronic pelvic inflammatory disease secondary to a gonorrhea infection or a man with a low sperm count. This population is currently the only group recognized by the clinical definition of infertility. For 30% of heterosexual couples who are involuntarily childless, no medical cause can be identified after the standard infertility evaluation (The Practice Committee of the American Society for Reproductive Medicine 2013). These couples are diagnosed with "unexplained infertility," with the presumption that there is a physiological etiology, but it cannot be identified. Because they meet the criteria of the clinical definition of infertility, heterosexual couples with unexplained infertility are presented with the same treatment options as other physiologically infertile heterosexual couples.

It is sometimes mistakenly assumed that physiological infertility affects only heterosexual couples, and social infertility is limited to LGBTQ couples. Yet, physiological infertility and social infertility are not mutually exclusive. While single women and lesbian couples are socially infertile due to their relationship status, they may also suffer from physiological infertility. Heterosexual couples can also experience both physiological infertility and social infertility. For example, take the case of a heterosexual couple in which the man has poor sperm motility (physiological infertility) and the woman has a strong preference against vaginal intercourse due to a history of sexual trauma (social infertility). Both their physiological and social infertility contribute to their difficulty conceiving as a couple. Heterosexual individuals can be physiologically fertile but socially infertile as in the case of a single heterosexual woman.

It was not until 2013 that the ASRM formally recognized the medical needs of socially infertile people and discouraged fertility specialists from restricting ART access to this population (The Ethics Committee of the American Society for Reproductive Medicine 2013). Although it was an important step for the ASRM to strongly recommend nondiscriminatory access to ART, regardless of a patient's sexual orientation or relationship status (The Ethics Committee of the American Society for Reproductive Medicine 2013), the organization stopped short of redefining clinical infertility. While this policy statement may influence the actions of healthcare providers, it does not necessarily affect the insurance industry. In fact, despite the reproductive medicine community's recent acknowledgment and acceptance of social infertility—including the World Health Organization's announcement in 2016 that it would expand its definition of infertility to include single individuals and LGBTQ individuals (Bodkin 2016)—health insurance companies in the United States still base infertility coverage on the narrow clinical definition, generally denying ART coverage to individuals with social infertility.

The Impact of Infertility

One common criticism of ART coverage is that infertility, and especially social infertility, is not a "real" disease because it does not cause physical harm. It is important to recognize that some diseases that cause physiological infertility may also manifest physical symptoms and are therefore indicated for medical interventions. For instance, in some cases, endometriosis can cause dyspareunia, or pelvic pain, and can also potentially cause infertility. A woman who is experiencing pelvic pain should clearly receive treatment for such pain. However, if this same woman has no physical symptoms, there would be no reason to undergo treatment unless she intends to conceive a child. Indeed, most physiologically infertile women will never know they are infertile until they attempt to become pregnant. Can a woman in a heterosexual relationship with no desire to have a biological child with her male partner suffer from infertility? The diagnosis of infertility and the decision to seek treatment rely heavily on social and situational factors and the individual's desire to become a parent. A diagnosis of physiological or social infertility may not have much impact on those with no desire to have children. However, the same diagnosis would keenly impact another woman whose identity and life goals include becoming a genetic mother. Both the intent to achieve pregnancy and the inability to conceive are necessary for a clinician to diagnose someone with infertility.

Some dismiss the desire to have biological children as unimportant or at least not within the medical purview. Yet, this criticism fails to recognize the psychological harms associated with infertility. According to a Pew Research Center report in 2011, 27% of childless men and 36% of childless women between ages 15 and 44 reported "it would bother them a great deal" if they never have children (Livingston and Parker 2011). In another 2010 survey, Pew found 60% of surveyed childless women under the age of 50 and 63% of childless men under age of 60 reported they want to have children one day, regardless of their marital status. Up to 83% of unmarried individuals who would like to get married in the future indicated that they wanted children one day. But even among single people who have no plans for marriage, 31% of them still reported a wish to have children someday (Pew Research Center 2010).

Infertility creates a low-control stress situation, in which individuals lack the ability to influence the outcome (Terry and Hynes 1998), and is a significant psychosocial stressor comparable to death of a family member or somatic disease such as cancer or HIV (Baram et al. 1988; Domar et al. 1993). In previous studies on involuntary childlessness, individuals who meet the clinical definition of infertility have shown increased risk of depression, anxiety, guilt, grief, sexual problems, reduced relationship satisfaction, and marital distress (Kraft et al. 1980; Möller and Fällström 1991; Lukes and Vacc 1999; Peterson et al. 2003; Sundby et al. 2007; Luk and Loke 2015). Infertility also contributes to social isolation, reduced self-esteem, loss of identity, and poor body image (Luk and Loke 2015; Whiteford and Gonzalez 1995; Wirtberg et al. 2007). Chronic adverse effects on interpersonal and social relationships secondary to distress precipitated by infertility have been reported even 20 years after failed pregnancy attempts (Whiteford and Gonzalez 1995). Despite significant emotional distress, many infertile women do not seek professional counseling or participate in support groups (Sundby et al. 2007), which may be because of the shame and stigma associated with infertility. Not surprisingly, involuntarily childless individuals reported reduced quality of life in comparison with individuals who have children (Chachamovich et al. 2010).

Much of medicine today focuses on treating conditions that may not be life-threatening but that significantly impact people's quality of life, such as seasonal allergies, back pain, anxiety, poor vision, and sexual dysfunction; and infertility is no different. The psychosocial harms of infertility are not limited to heterosexual, cisgender couples. All individuals, regardless of their relationship status, who want biological parenthood but are unable to achieve it may suffer from infertility. Socially infertile women have the same intent to become biological parents as their physiologically infertile counterparts and can suffer the same psychological harms associated with infertility. For these reasons, we believe social and physiological infertility should be recognized as the same illness with different etiologies.

Although heterosexual, cisgender couples are culturally elevated as ideal parents, or at least the norm, many single individuals and LGBTQ couples also desire parenthood. Furthermore, contrary to dominant cultural narratives, single individuals and LGBTQ couples can be good parents, and their children are generally just as well adjusted as children raised in heterosexual, two-parent households.

As of 2008, 25% of American children lived in single-family homes (Pew Research Center 2010). The increase in single-parent households in the United States reflects changes in family structure. Many single families have extended social support such as aunts, uncles, grandparents, and godparents that help the single parent to raise the children. Although single-parent households historically have faced significant stigma, 86% of participants surveyed in 2010 consider a single person with a child to be a family (Pew Research Center 2010), which shows that the cultural definition of family has expanded to include single-parent households. The majority of single-parent families are single mothers. Traditionally, these single-mother families have been associated with divorce, separation, or unplanned pregnancy. However, there is a growing trend of single motherhood termed "solo mothers." These are women without a partner who chose to enter parenthood and conceive children through donor insemination (Weissenber et al. 2007). A sharp increase of this "non-standard request" at the fertility clinic has been observed in recent years as more single women decided to pursue single motherhood before their fertility declines (Golombok et al. 2016). Many of the 31% of surveyed heterosexual single persons who wanted children one day but did not want to marry would likely use ART if they were ultimately unable to find a willing and appropriate opposite-gender partner. Their desire to have biological children is no different than individuals in heterosexual relationships who are using ART due to physiological infertility.

Although children raised in a single-family home may face some disadvantages such as less parental time and lack of two-adult income, children raised in stable single family do not suffer from significantly worse cognitive development, health outcome, or school performance compared to children raised in two-family homes. In fact, family stability appears to be a more important factor in children outcome. Children raised in stable single-parent homes, after taking consideration of confounding factors, show no significant differences in cognitive development or behavior issues compared to children raised in stable two-parent homes (Waldfogel et al. 2010). Similarly, the maternal education level appears to have a stronger correlation to a child's school performance than the family structure (Amato et al. 2015). Children raised in a loving, supportive, and stable single-parent home with extensive social support network are therefore not at a significant disadvantage compared to children raised in other family structures.

Just like many heterosexual single individuals, many LGBTQ individuals desire biological parenthood. According to the Pew survey, 28% of childless LGBT adults under age 60 would like to have children one day, while 34% remained undecided (Pew Research Center 2013). Although the stigma in our society against single parenting appears to be in decline, the prejudice against same-sex couple parenting remains high. According to the 2010 Pew Research Center survey, only 63% of respondents considered a same-sex couple with children to be a family, compared to the 86% of respondents considered single parent with children to be a family (Pew Research Center 2010). This indicates a persistent bias against LGBTQ couples. The legalization of same-sex marriage in the United States has encouraged LGBTQ couples to engage in heteronormative activities, such as starting two-parent families and raising children (Hopkins et al. 2013). Interestingly, the public is more likely to classify a same-sex couple as “a family” when they are raising children together. Only 45% surveyed respondents considered same-sex couples without children a family, in comparison with 63% for same-sex couples with children. The presence of children in a same-sex household appears to have a legitimizing effect on the relationship and allows them to be further assimilated into society. This is yet another reason why same-sex couples may wish to have biological children.

Societal arguments against LGBTQ parents and families are often disguised as concern for the children but are constructed to justify discrimination against LGBTQ parents in an effort to maintain a heterosexist status quo (Clarke 2001). In a study reviewing 21 empirical studies on the outcome of children born to planned lesbian families compared to children born to planned heterosexual families, there have been no significant differences in the cognitive functioning, emotional development, or peer relationships. Children from the planned lesbian household, however, showed less aggressive behaviors. Mothers from these planned lesbian families also shared parenting responsibilities more equally, with a higher quality of parent-child interaction and parenting awareness skills (Bos et al. 2005).

Even if one is supportive of single women and LGBTQ couples having children, it is frequently suggested in public discourse that people suffering from infertility (physiological or social) should choose to adopt rather than undergo ART (Davenport 2016). However, the process of adoption is also costly and time-consuming. Depending on the type of adoption and adoption agency, it may cost up to $50,000 (Child Welfare Information Gateway 2016). Although there are loans, grants, and tax credits available to lessen the cost of adoption, the financial burden of adoption is comparable to the cost of undergoing at least two ART cycles. Since infertility is a long-term stressor associated with personal identity and the social expectation of one’s ability to conceive a biological child, adoption may not necessarily resolve the psychological and emotional burden of infertility. Moreover, some couples highly value both partners sharing biological kinship with each of their children, thus making adoption a less appealing option to start a family. Lesbian couples can both share biological parenthood with their children, which is typically defined as experiencing gestation and/or being genetically related to the child, via in vitro fertilization (IVF) by fertilizing one partner’s oocyte with donor sperm and transferring the embryo to the other partner for gestation (Marina et al. 2010).

Additionally, single women and lesbian couples may face additional barriers in trying to adopt since some adoption agencies will not place children with single parents and LGBTQ couples. A single individual may face significant difficulty adopting children due to the social stigma attached to single parenthood, especially against single women (Pakizegi 2007). LGBTQ couples may encounter homophobia and heterosexism biases present on the individual, interpersonal, and organizational levels of an adoption agency that prevent children placement (Ryan et al. 2004).

Insurance Coverage for Social Infertility

Demonstrating medical necessity is the main hurdle many single women and lesbian couples face when seeking reproductive assistance, especially in states without an infertility insurance mandate. Because social infertility is currently not a recognized medical condition nor is it part of the broader diagnosis of infertility, it is deemed medically unnecessary by the insurance companies. Broadening the current clinical definition of infertility to include social as well as physiological infertility recognizes that single people and LGBTQ couples will likely need the assistance of a fertility expert since they will not be able to conceive through sexual intercourse.

While this change in the clinical definition of infertility may seem too radical for some, it is worth noting that infertility is a relatively new medical condition. A heterosexual couple's inability to conceive a child was historically considered to be a private issue, not a public or medical problem. It was not until the 1950s, in conjunction with the development of fertility medications, that infertility became a recognized medical condition (Greil 1991). The labeling of physiological infertility as a medical condition meant that heterosexual couples were justified in seeking and receiving medical assistance in having biological children. Social infertility is slowly becoming recognized, especially as prominent lesbian celebrities, such as Wanda Sykes and Melissa Etheridge, publicly discuss using ART to have children (Long 2015). Similar to physiological infertility, social infertility has entered the public consciousness as a social issue that can be solved with the same medical technologies that many heterosexual couples have had access to for years.

Once social infertility becomes part of the clinical definition of infertility as a medical diagnosis, socially infertile individuals can become eligible for insurance coverage (though perhaps only in states where infertility is covered by insurance), and their reproductive goals would be legitimized by the medical community (Murphy 1999).Without insurance coverage, only the privileged and wealthy can afford ART (Greil et al. 2011; Bell 2016). A single round of IVF is estimated to range between $12,400 and $27,000 for women without insurance coverage (Nachtigall et al. 2012). The per successful outcome (i.e., a live birth baby), however, may cost over $61,000 (Katz et al. 2011).

According to the FertilityIQ employment report, less than 27% surveyed Americans who underwent fertility treatment received insurance coverage for the service (FertilityIQ 2017). In the states that mandate the group insurers to offer variable degree of infertility benefit to employers, religiously affiliated and small employers are generally exempted as well (Devine et al. 2014). Even in the states with a comprehensive fertility insurance mandate, ART is covered by insurance solely for heterosexual couples based on the current clinical definition of infertility. This narrow definition allows insurance companies to deny ART coverage to paying members who do not engage in coupled heterosexual intercourse while providing coverage to members who do. Without adequate insurance coverage, the unaffordability of ART procedures becomes a barrier to single women and lesbian couples seeking to start a family via reproductive assistance.

In the United States, only 15 states currently require health insurers to offer coverage for infertility diagnosis and treatment (RESOLVE 2017).[2] Of these 15 states, Massachusetts offers the most inclusive health insurance coverage due to the 2010 amendment that changed the definition of infertility to "a condition of an individual who is unable to conceive or produce conception during a period of year if the female is under the age of 35, or during a period of six months if the female is over the age of 35." The Massachusetts definition of infertility does not rely on the "married individual" qualifier found in the Rhode Island mandate or the "unprotected intercourse" requirement of the New Jersey mandate (National Conference of State Legislature 2017). The Massachusetts mandate also covers both the primary beneficiary and her or his spouse. There are also fewer limitations on the types of procedures or number of treatment cycles a woman can undergo under the Massachusetts mandate (Basco et al. 2010). The Massachusetts review system allows new medical technologies to be incorporated into coverage as they mature. Most importantly, Massachusetts has broadened the coverage for single women and lesbian couples who have attempted low-tech conception methods (Health Policy Commission Office of Patient Protection 2013).[3]

Besides Massachusetts, Illinois is another state to provide a potential pathway for lesbian couples and single women to resolve childlessness via ART. The Illinois mandate covers women after "efforts to conceive as a result of one year of medically based and supervised methods of conception, including artificial insemination, have failed and are not likely to lead to a successful pregnancy" (Illinois Department of Insurance 2014). In April 2017, New York State became the third state to mandate infertility coverage for lesbian couples and single women by insurance companies (New York State Financial Services 2017). However, the current clinical definition of infertility still perpetuates the stigma and bias against single women and lesbian couples, potentially delaying their access to ART. As of 2017, only Massachusetts, Illinois, and New York mandate broad insurance coverage of all women regardless

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[2] The 15 states that currently require health insurers to offer coverage for infertility diagnosis and treatment are Arkansas, California, Connecticut, Hawaii, Illinois, Louisiana, Maryland, Massachusetts, Montana, New Jersey, New York, Ohio, Rhode Island, Texas, and West Virginia.

[3] Although the Massachusetts infertility mandate has the most extensive ART coverage in the United States, it still does not include surrogacy. Single men and gay couples therefore will not receive coverage for all of the technologies and services they need to build a biological family.

of their relationship status. A more inclusive approach to infertility insurance coverage in other states would benefit socially infertile individuals throughout the country, especially for non-hetero, non-coupled, and nontraditional families.[4]

One potential concern with expanding the clinical definition of infertility is that it may cause insurance premiums to increase in states with infertility insurance coverage. If social infertility became a recognized and treatable medical condition, it would be hard to justify the continued exclusion of single individuals and LGBTQ couples, especially since these previously excluded populations have already been paying the same premiums to support the cost of infertility treatment for heterosexual couples. It is also worth noting that while ART is quite expensive for individuals, it makes up a very small percentage (only 0.06% in 2009) of the total healthcare expenditure in the United States (Chambers et al. 2009). Another potential concern with a broader definition of infertility is that the utilization of ART will also likely increase. Yet, many other factors have recently contributed to an increased utilization of ART, such as the normalization of such technologies, increased insurance coverage for ART (due to state mandates and insurance company policy changes), and "delayed" childbearing among women. Continuing to deny ART to single women and LGBTQ couples while simultaneously expanding its use among other groups does not seem to be a tenable position. Expanding the definition of infertility may entail financial implications. However, we should not allow speculative economic considerations to prevent us from upholding reproductive justice and providing access to ART for single and lesbian women.

Conclusion

In this chapter, we have claimed that social and physiological infertility may be viewed as the same illness with different etiologies. The recognition of physiological infertility as a medical condition has allowed some heterosexual couples to receive insurance coverage for certain types of ART. Only Illinois, Massachusetts, and New York provide some insurance coverage for the socially infertile women. The remaining 12 states that currently also require some insurance coverage for infertility unfortunately exclude single individuals and the LGBTQ community. The current definition of infertility is written under a heteronormative assumption of what constitutes a family and prevents socially infertile people from accessing treatments that may meet their medical needs.

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[4] Male infertility care is often overlooked in discussions of infertility. Although almost half of the infertility cases among heterosexual couples are caused by male factors, only six states (California, Connecticut, Massachusetts, New Jersey, New York, and Ohio) mandate coverage for male infertility care. Two other states (Montana and West Virginia) mandate undefined infertility services only for health maintenance organization plans. Among these states, Massachusetts once again provides the most comprehensive coverage for male infertility treatment, including sperm procurement, processing, banking, as well as reversal of elective sterilization (Dupree 2016). However, the Massachusetts coverage plan is designed only for males in heterosexual relationships.

We have proposed an expanded clinical definition of infertility that recognizes the contribution of both social and physiological factors to infertility. We asserted that a more inclusive definition of infertility will provide single individuals and LGBTQ couples in states with infertility insurance mandates improved access to ART. Future work is needed to examine and compare the psychosocial and emotional effects of involuntary childlessness among single individuals, LGBTQ couples, and heterosexual couples. The impact of infertility may have different or worse effects on the socially infertile as they face many different hurdles to achieving biological parenthood.

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Social Responses to the Environmental Impact of Reproduction in the Global West: A Critique of Christine Overall's "Overpopulation and Extinction"

Philipa Friedman

In her book entitled *Why Have Children?*, Christine Overall addresses ethical implications of procreation for the most part from the perspective of Western heterosexual couples who are considering whether or not to have biological children. She argues that couples ought to justify their reasons *for* reproducing rather than having to defend their choice *not* to reproduce. In subsequent chapters, Overall discusses moral considerations surrounding the choice to procreate, drawing from diverse arguments that populate the literature on reproduction. In chapter 9 of her book, Overall considers arguments against reproduction that stem from the overtaxing of Earth's resources and issues of overpopulation. Ultimately, she concludes that we have a moral obligation—although not a legal or social one—to procreate at a replacement rate, which is to say that every person is entitled to one biologically related child. Overall's argument in favor of replacement-rate reproduction misses the point in that it addresses a widespread socio-environmental phenomenon with a highly individualized moral recommendation to limit reproduction based on personal choice. The environmental issues surrounding reproduction in the global West would be more effectively addressed using an ecofeminist approach emphasizing social and educational reform than by personal moral reflection.

In beginning my argument, it will be helpful to first provide a brief overview of the ecofeminist framework within which I am working. Karen Warren characterizes ecofeminism as drawing on "feminism, ecology and environmentalism, and philosophy in its analyses of human systems of unjustified domination" (Warren 2000: 43). She goes on to elaborate that "there are important interconnections among the unjustified dominations of women, other human Others, and nonhuman nature" (Warren 2000: 43). Understanding these intersections is vital in determining solutions to these issues of domination, she argues, as to address either issues of ecological domination or of gendered domination simply is to address the other.

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Ecofeminist activism has inherently to do with advancing policies and practices which pertain to a particular intersection between issues of gender equality and environmental care. To say that the two issues are importantly related is not to state outright that any solution to one of these problems will automatically be a solution to the other. Rather, it recognizes an important relationship between women and the environment and women *as* an environment. Further, the ecofeminist movement recognizes that this relationship means, not that all solutions to one are solutions to both but that the *best* policies and practices used to address one issue will inherently improve the other. According to Warren, “ecofeminist philosophy is not, is not intended to be, and should not be limited to ‘describing’ reality or reporting ‘facts’; it involves advancing positions, advocating strategies, and recommending solutions. This prescriptive aspect of ecofeminist philosophy is central to doing philosophy” (Warren 2000: 43). It is in this prescriptive element I hope to advance in my project; I want to recommend and justify social and political ways to simultaneously improve the conditions of women and of the environment. In this case, my aim is to advance and justify policy recommendations that benefit women, particularly low-income women and women of color in the global West, by improving access to education and economic opportunity. Greater access to education and economic opportunity will then simultaneously benefit the state of the environment by reducing the number of overall births to women in the global West.

In chapter 9 of her book, *Overpopulation and Extinction*, Overall establishes the environmental issues that inform reproductive choices for couples in the West. She acknowledges that overpopulation, while problematic, is not necessarily the main problem at work in developed nations (Overall 2012: 178). Rather, overpopulation is of greater concern in developing areas where women are less likely to have access to birth control and education. However, Overall cites Corinne Maier in asserting that overconsumption on the part of developed nations poses an extreme threat to the environment. Maier writes, “It’s not that there are too many people on the planet—there are just too many *rich* people” (Overall 2012: 178). Overall elaborates that “in general, children in developing countries generate less net cost to the environment that children in developed countries… [P]lanetary capacity is not merely a matter of how many human beings there are, but how those human beings live their lives” (Overall 2012: 179). People in the West consume a great deal more than in other areas; Overall cites Scott Wisor when she writes that, for example, “one U.S. citizen consumes as much energy is 900 Nepalis” (Overall 2012: 186). Overall therefore concludes that “Because of the dangers of planetary overload, the responsibility to limit the number of one’s offspring falls on the people living in the developed world” (Overall 2012: 179).

While Overall acknowledges that we in the West have a responsibility to limit our number of offspring, this responsibility is entirely an ethical one; she writes that “we in the developed world have a moral responsibility to limit our numbers, given the current threats to planetary capacity posed by overpopulation” (Overall 2012: 179). The moral nature of this responsibility is consistent with the conclusion that she establishes in previous chapters, which she recapitulates in the introduction to chapter 9; she writes that “Human beings have a right *not* to reproduce” but that they also have "a right to reproduce in the negative or liberty sense" (Overall 2012: 174). Thus, because human beings have the right to refuse to procreate, it is logically consistent that they may also have some additional moral obligation not to. However, because we also have a negative right to procreate (in other words, no one can interfere legally or physically with our ability to have children), there can be no positive provision forbidding couples or individuals from reproducing. Overall holds up China's One Child Policy as an example of such a positive legal provision against procreation and gives some additional reasons why it would be ineffective; it has resulted in a skewed ratio of males to females given that female fetuses are often aborted and female infants (more often than male infants) are exposed or abandoned, an imbalance between the elderly and youth who are available to take jobs caring for them and a state of affairs in which there is only one child to care for two aging parents. A legal provision limiting procreation in the West is, therefore, from a rights perspective infeasible and from a consequences perspective undesirable. Consequently, Overall turns to a model of personal moral responsibility in order to curb reproduction in developed nations.

Overall writes that limiting our reproduction is a responsibility of the developed world for a number of reasons. First, "most of us living in the global West are on average well educated. As a result, we know (or should know) about the dangers of overpopulation," but further "we collectively are also sufficiently informed to know how to curb our numbers" (Overall 2012: 179). Second, "we in the West consume far out of proportion to our numbers" (Overall 2012: 179). I would also add to this second point that the consequences of that consumption is largely outsourced; because we no longer produce the bulk of what we consume, pollutants and other consequences of large-scale production fall on nations which are not so developed. Third, "we in the West have the ability—the research, resources, and technologies—to limit the number of children we have" (Overall 2012: 179). This is to say that we in the West have the most access to the best forms of birth control currently available, and so we are more able to effectively and safely control our reproduction. Given all of these advantages and the many consequences of our proliferation, it does certainly seem to fall to us in the West to take steps to limiting our population. Overall writes that "Entire societies must take responsibility for curbing population growth; decisions must be made and policies enacted on a national level" (Overall 2012: 180). However, she remains steadfast in her assertion that the decision not to reproduce is a personal one; she continues, "Nonetheless, population will not stabilize, let alone decline, without active decisions being made by individuals. Societies do not have fewer babies; individuals do" (Overall 2012: 180).

Overall goes on to develop this personal moral responsibility model for limiting reproduction. She cites Thomas Young in acknowledging that procreation in the global West is fraught with ethical issues; she quotes him in saying that "having even just one child in an affluent household usually produces environmental impacts comparable to what mainstream environmentalists consider to be an…unacceptable level of consumption, resource depletion, and waste" (Overall 2012: 181, citing Young) and that human procreation is therefore "morally wrong in most cases" (Overall 2012: 180).

Consumption, resource depletion, and waste certainly are a significant problem in the global West, and in the United States in particular. According to energy consumption information published by the University of Michigan's Center for Sustainable Systems in August 2016, the United States comprises approximately 5% of the world's population and yet consumes at least 18% of the world's energy (University of Michigan 2016). Further, "Each day, U.S. per capita energy consumption includes 2.5 gallons of oil, 13.7 pounds of coal, and 234 cubic feet of natural gas" (University of Michigan 2016). To compare energy consumption in the United States with the energy use of a developing country, let's take a look at India. The population of India is approximately 1260 million people, while that of the United States is about 314 million, yet the United States uses over four times as much energy as India does (World Population Balance 2015). In rough equivalency terms, a woman in India would have to have 17 children in order to equal the lifetime consumption of just one American child (World Population Balance 2015). Indeed, on average, one American consumes as much energy as 6 Mexicans, 31 Indians, and 370 Ethiopians (International Business Guide 2016). Given that this energy is still source primarily from fossil fuels, this high level of consumption is also contributing to resource depletion and the rise in global temperature. The average American also uses 159 gallons of water daily, compared with over half of the world's population that lives on 25 gallons (International Business Guide 2016). In terms of waste, each person in the United States generates about 5.7 pounds of garbage each day, much of that edible food waste (International Business Guide 2016). Ultimately, given the rate and amount of American consumption of energy resources, food, and water, if every country consumed at the same rate as the United States, we would require 4.4 Earths to sustain us (International Business Guide 2016). Given the statistical evidence that Americans dramatically out-consume their counterparts in the developing world, it seems obvious that procreation in the United States—and likely much of the global West—presents grave ethical concerns.

Despite this strong, evidence-based claim, however, Overall disagrees "with Young's idea that westerners…should give up procreation altogether" (Overall 2012: 181). She writes that "an obligation not to have any children at all would be a huge sacrifice, one that is too much to expect of anyone who wants to have children" (Overall 2012: 181). Here, Overall already sets a precedent that individual preference trumps the pressing environmental concerns surrounding reproduction in a context of wealth and privilege. Instead, she proposes "a one-child-per-person morality," whereby every person is entitled to produce one genetically related child (Overall 2012: 183). Every single person is entitled to a single child, and couples are entitled to two between them. She argues that this moral recommendation will be easier to follow than a one-child-per-couple policy, that it implicitly endorses the value of every adult as worthy of being reproduced, and that it will "eventually result in population decline, given that some people will have no children and some couples will choose to have only one" (Overall 2012: 183). It bears repeating, perhaps, that this moral recommendation cannot ever be, as per Overall's own view, a legal policy in any nation given that we have a negative right to reproduce. Rather, the choice to adhere to this recommendation lies purely with the individual or couple considering whether or not they will have a child or children.

There seem, even prior to a larger ethical critique of this view, to be several practical issues with a one-child-per-person morality. The first of these concerns is that it fails to account for instances of accidental pregnancy, which can be prevalent; in the United States in 2011, approximately 45% or 2.8 million of the 6.1 pregnancies in the United States were unintended (which is to say either mistimed or unwanted) (Guttmacher Institute 2016). My second practical concern is that many couples may choose to have more than one child per person despite their personal moral feeling about the ethical status of procreation in a social context of high consumption, energy use, and waste.

Given the urgency and severity of the environmental stakes of reproduction in the Western world, I cannot imagine that Overall's one-child-per-person morality could be sufficient to curb the number of offspring we in the West produce in time to halt or reverse the damage we have already done to our Earth and to the other parts of the world that bear the brunt of that damage. Although she asserts that her moral recommendation can apply to everyone, even those whose religious beliefs might preclude the use of birth control or the limiting of offspring (Overall 2012: 188), Overall's own claim that an individual's or a couple's desire to procreate trumps the concern that procreation might nearly always be immoral in the West sets a precedent that having children is more important to individuals than adhering to moral recommendations. Simply put, if a person wants a third child—whether because they really wanted a girl or just because they want a big family—they will have that child in spite of any number of moral considerations.

Fortunately, Overall does provide a way into answering this problem of couples having children despite their own moral concerns. This answer is a social one, despite her explicitly individualistic framework for reproductive choice. She writes in her introduction that "Because the context of procreation is political"—and I would add social and economic, as well—"reproductive decision making cannot realistically be discussed outside of a feminist framework" (Overall 2012: 9). I will argue, therefore, that limiting reproduction in the global West is a matter of implementing widespread social change and applying policies that empower women to make informed choices about childbearing and rearing.

It is perhaps worth noting here that Overall's reflection is explicitly moral in nature, while my proposed turn to education and policy represents a potential social and political solution to the issue of overpopulation in the West. This turn is significant in part because of the ambiguous nature of the moral claim that we ought to bear environmental concerns in mind when deciding whether or not to have children; should the environment be preserved because it is intrinsically good? Do we have obligations to future generations of human beings such that we ought to attempt to conserve resources and maintain a suitable ecosystemic balance for their sake? These questions are ones which have not been conclusively answered even in many volumes.

The sociopolitical approach, drawing from ecofeminist thought, identifies problems that exist presently and which have an impact both on women and on our environment. The problem I identify in this paper is that women, particularly low-income women and women of color, do not necessarily have the educational or financial resources or motivations to forego childbearing, resulting in a higher overall birth rate in the global West, the region most likely to overconsume. The ecofeminist approach attempts to suggest or deliver solutions to those problems, solutions that simultaneously benefit both women and the environment. This is an important feature of the ecofeminist approach; we ought not address feminist issues for the sake of the environment, nor ought we address environmental issues for the sake of women. Rather, oppression of one *is inherently* oppression of the other, and the effects of this relationship are already evident globally. Diane-Michelle Prindeville provides the example of Navajo and Pueblo communities whose lands in New Mexico have been co-opted by mining companies attempting to meet increasing demands for mineral resources (Prindeville 2004: 94). These mining operations cause tremendous environmental destruction, and the toxic runoff from these facilities is not only causing widespread health concerns like asthma, but it is now evident in the breast milk of women living in those Navajo and Pueblo communities (Prindeville 2004: 94). Women's bodies, and specifically those women living in poverty who are most at risk of environmental degradation-related health concerns, have become the very site of environmental oppression. The best long-term solution is fewer human beings whose demands for resources must increasingly be met with environmentally toxic practices.

We see, therefore, that in addressing the disproportionate effects of environmental degradation on women in low-income communities and communities of color, our solution must be one that improves the ability of these same women to choose when to have children and how many they want to have.

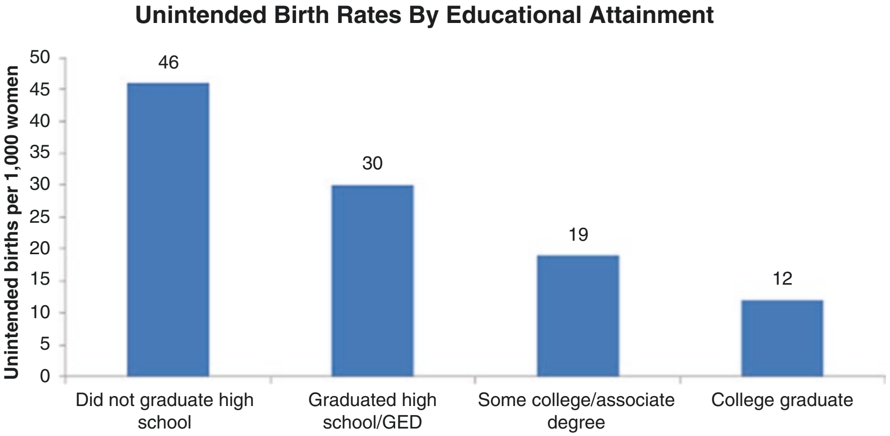
There are many factors that determine how many children an individual woman or a woman in a committed couple will have in her lifetime. While access to birth control, Plan B, women's health and family planning resources, and abortion services are instrumental in giving women more control over their reproductive choices, the most significant factors in determining how many children a woman will have are education and economic opportunity. According to the Population Reference Bureau's 2012 Fact Sheet on United States fertility:

> longer-term fertility trends may depend on future trends in women's employment and earnings relative to men.[8] Women outnumber men in college and make up a growing share of the labor force. The [2008] recession hit male-dominated jobs the hardest, contributing to a growing share of women who now outearn their husbands.[9] As more women become primary breadwinners, fertility decisions are more likely to hinge on women's earnings than they did in previous decades. A growing reliance on women's employment and earnings could further dampen U.S. fertility rates in the coming decades. (Mather 2012)

Whether or not a woman chooses to take advantage of birth control or abortive options depend first on whether or not she is sufficiently educated to know how to take advantage of those options, second whether she can afford them, and third whether she has the financial motivation to delay or forego childbirth and/or childrearing altogether. These factors tend to have racial and socioeconomic implications. For example, 2012 data suggests that fertility rates among Latinas and black women have dropped in recent years to rates more similar to those of white women, which correlates with higher rates of enrollment in college (Mather 2012). The

Population Reference Bureau reports that “Among 18–24-year-olds, more women than men are enrolled in college in every racial and ethnic group” (Mather 2012). College enrollment, in turn, is correlated with higher future earning power and a greater presence in the job market.

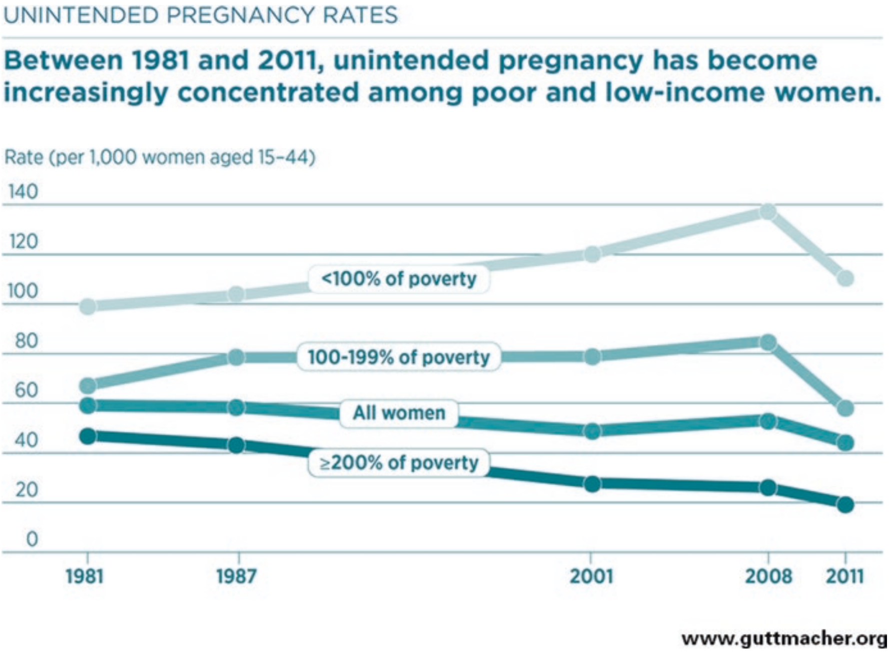
Conversely, lower levels of education tend to correlate with higher numbers of children and higher rates of unplanned pregnancy in particular. According to the Brookings Institute, “unintended birth rates are nearly four times higher for high school drop outs than for college graduates” (Sawhill and Karpilow 2013). Further, rates of unintended pregnancy drop steadily as the level of education increases. (See Unintended Birth Rates by Educational Attainment, below (Sawhill and Karpilow 2013)).



The Brookings Institute found that while increased and low-cost access to birth control is an effective short-term measure for preventing unintended pregnancy, the more effective solution would be to ensure the education of disadvantaged women. According to their findings:

> In the short run, reducing unintended pregnancy will require significant changes in contraceptive behavior. For instance, the Choice Project—a program that provided no-cost contraception to nearly 10,000 women in the St. Louis region (many of whom were unmarried and from low socio-economic backgrounds)—shows that getting women onto highly effective, low-maintenance forms of contraception (e.g., IUDs or implants) can massively reduce the incidence of unintended pregnancy. In the longer term, however, radical reductions in unintended childbearing will require improving the educational attainment and economic prospects of the most disadvantaged. (Sawhill and Karpilow 2013)

Statistics furnished by the Guttmacher Institute support this conclusion: according to their findings, unintended pregnancy rates are highest among poor- and low-income women and minority women (Guttmacher Institute 2016). Indeed, “the rate of unintended pregnancy among poor women (those with incomes below the federal poverty level) as 112 per 1,000 in 2011, more than five times the rate among women with incomes of at least 200% of the federal poverty level” (Guttmacher Institute 2016).



There is also a stark divide in unintended pregnancy rates along racial lines: “At 79 per 1,000, the unintended pregnancy rate for black women in 2011 was more than double that of non-Hispanic white women (33 per 1,000)” (Guttmacher Institute 2016).

It is worth noting here that, even in the case of our nation’s poor, poor Americans tend to out-consume the poor in other countries. Peter Singer writes in *The Life You Can Save* that:

> In wealthy societies, most poverty is relative…In the United States, 97 percent of those classified by the Census Bureau as poor own a color TV. Three quarters of them own a car. Three quarters of them have air-conditioning. Three quarters of them have a VCR or DVD player. All have access to healthcare. (Singer 2010, 8)

Thus, even the poor in the United States consume, in a relative sense, a substantial amount of resources. Even if higher birth rates are concentrated among the United States’ poor, those births still represent a greater level of consumption than high birth rates in developing nations. This level of consumption has to do not only with a culture of consumption but also with hidden resource costs associated with owning or eating certain things, such as the water usage of beef versus soy or wheat. It is therefore still in the best interest of the environment to curb fertility rates across socioeconomic lines in the United States, particularly in terms of preventing unintended pregnancy.

Rates of pregnancy, then, are not simply a matter of individual choice. Rather, we can identify significant socioeconomic, racial, and educational factors that contribute to birth rates in developed nations, and in the United States in particular. The nature of these factors belies Overall's claim that curbing fertility in the global West is a matter of personal choice. While personal reflection is certainly warranted when deciding whether or not to have a child, Overall's personal moral reflection method seems to miss the point that pregnancies, and especially the factors that contribute to pregnancy, are not always chosen.

Given the facts of pregnancy in the United States, a country in which women of color have a greater chance of living at or below the poverty line and those who are poor and uneducated tend to have higher rates both of fertility and unintended pregnancy, the way forward seems clear. The very best way we can curb fertility and therefore overconsumption in the United States is to improve access to and quality of education, particularly for lower-income women and women of color. I have already demonstrated that education in general tends to benefit women and women of color in particular by improving their opportunities for employment and reducing the number of unplanned pregnancies that they experience. Keeping women in school, preferably through the university level, is the most effective way to achieve a substantial reduction in the national rate of fertility. A higher level of educational attainment, in turn, translates into greater earning potential and more job opportunities, which tend to correlate with childbearing later in life. Access to quality education, therefore, serves the dual purpose of empowering women and curbing our national ecological footprint. Clearly, there is a great deal more to be said about education attainment and fertility, but it is a larger discussion than I currently have room to address.

Now that we have established the benefits of education in general for reducing fertility rates, the next natural step is to discuss sexual education in particular. According to a Planned Parenthood memo on reducing teenage pregnancy in the United States:

> Only 11 states plus the District of Columbia require sex education that includes information about contraception. Six other states require that if sex education is provided, it must include information about contraception (Frost et al. 2013). Recent studies show that more teens receive formal sex education on "how to say no to sex" (87 percent of teen women and 81 percent of teen men) than on contraception methods (70 percent of teen women and 62 percent of teen men).

Abstinence-only sexual education does not address contraception or consequences of sexual intercourse, which include sexually transmitted infection and, most importantly for our discussion, unintended pregnancy. This gap in sexual education is particularly troubling given the young age of first sexual activity. According to the Planned Parenthood memo, over 60% of teens have had sex by grade 12 (Planned Parenthood 2013). Further, many young people are unaware of the kinds of contraceptives that are available: "Half of teens have not heard of emergency contraception and do not know that there is something a woman can do to prevent pregnancy after unprotected sex" (Planned Parenthood 2013). Sexual education in the United States that is medically accurate and comprehensive, starts early, and continues through grade 12 is proven to be more effective at postponing first intercourse and preventing unintended teen pregnancy through higher rates of contraceptive use (Planned Parenthood 2013). Says Planned Parenthood:

> The most effective programs in the U.S. combine medically accurate information on a variety of sexuality-related issues, including abstinence, contraception, safer sex, and the risks of unprotected intercourse and how to avoid them, as well as the development of communication, negotiation, and refusal skills. Teens who have sex education are half as likely to experience a pregnancy as those who attend abstinence-only programs. (Kohler et al. 2008)

In other developed nations, comprehensive and medically accurate sexual education has resulted in teen birth rates that are between two and four times lower than those in the United States currently (Planned Parenthood 2013).

Sexual education early in life and through high school graduation, in turn, can have a tremendous impact later in life. Knowledge about contraception is a benefit to people of all ages, and a woman who is informed about the types of contraception at her disposal will have an easier time accessing and using whatever method she chooses. Furthermore, the "communication, negotiation, and refusal skills" (Planned Parenthood 2013), discussed by Planned Parenthood as a vital part of sexual education, no doubt prove useful later in life; we discussed earlier the ways in which a woman's bargaining power in a marriage due to career or financial success has contributed to lower birth rates in the United States. Along those same lines, learning how to negotiate in a specifically sexual or procreative context may help women to gain more control over their fertility in relationships or marriages. The benefits of a comprehensive sexual education are far reaching and help to limit fertility both in a woman's teenage years and beyond.

Education, and sexual education in particular, are not the only ways to limit the environmental footprint of the United States. The abolition of factory farm subsidies, funding for alternative energy research, and widespread advocacy for a vegetarian or vegan diet would all help to reduce the impact of our consumption. However, given the pervasive nature of the culture of overconsumption and the inertia of the policy that governs it, I do believe that the best way to limit our environmental impact is to limit our fertility. Given that there are systemic socioeconomic and political factors which contribute to fertility, as I have demonstrated, limiting our reproduction simply *cannot* be a matter of personal moral reflection, as Overall advocates. More and more effective education for women, and women of color especially, seems to be our best hope for limiting our environmental impact in the coming generations.

Here, I must address possibly the most significant potential objection to my argument; women of color in the United States ought understandably to be skeptical of any attempt, policy-based or otherwise, to curb their fertility. As Dorothy Roberts discusses in *Killing the Black Body*, this country has a terrible history of forced sterilization, and the imposition of other racists measures to ensure that women of color do not reproduce. Policy itself has been used to "keep Black women from having children" (Roberts 1997: 5). There can be no defense for those measures, and it is for this reason that, in my own recommendations, I focus on education of women rather than medical intervention as a way of reducing the national birth rate. Education, as opposed to medical intervention, expands a woman's options rather than diminishing them and, as I have demonstrated, also tends to lead to motivations to postpone childbearing. Roberts writes that the "traditional understanding of reproductive freedom" in the United States "has had to accommodate practices that blatantly deny Black women control over critical decisions about their bodies" (Roberts 1997: 6). It is my belief, however, that policy focusing on the education and sexual education of all women can improve a woman's ability to choose. In keeping with the ecofeminist approach, I believe that this focus on educational policy will do the dual work of improving the lives of women by offering them access to a greater array of educational and financial options and improve the state of our environment by ultimately lowering the national birth rate in highest-consuming country in the world.

Overall's argument that "societies do not have fewer babies; individuals do" sounds to me a little too much like the argument that "guns don't kill; people do." All this argument does is place the burden of controlling a massive social phenomenon on individuals who, because they are fallible and because they have understandable desires, often make immoral choices. Overall herself writes that "Individuals making choices about procreation should not and cannot be regarded as acting in a social void, independent of other people and relationships or outside of the broader culture in which they live" (Overall 2012: 13). The broader culture in which we live is one that values luxury and consumption. Therefore, our propensity in the West to consume much more than we need and to perpetuate that behavior in raising our children represents a pressing social issue. The solution, therefore, cannot be an individual one. If we are to effectively address the issue of overconsumption, overpopulation, and overtaxation of our resources, there will need to be a widespread social push to educate citizens of the global West not only about our reproductive decisions but also our consumptive behaviors more generally.

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Part III

Reflections on Assisted Reproductive Technologies

Decentering Whiteness in Feminist Bioethics: Assisted Reproductive Technologies (ART) as an Illustrative Case

Karey A. Harwood

Introduction

In a *New York Times* op-ed from May 2016 entitled "Is egg freezing only for white women?," Reniqua Allen reflected on whether to freeze her own eggs. Allen described herself as a professional woman in her 30s, unmarried, and African-American and explained she was considering freezing her eggs after a family friend nudged her to have children before it was too late, with or without a husband. In contemplating the option of egg freezing as a path to motherhood, Allen raised some questions about egg freezing that I had not seen directly addressed in the bioethics literature. Allen's biggest concern was that using egg freezing to have a child as a single black woman would mean becoming "a stereotype, a stigma." Her fear of being stigmatized constrained what she felt free to choose. In her words:

> Black women aren't given the luxury of having their nontraditional choices appear to be new and radical. When we make "unconventional" decisions around reproduction, we're stigmatized. Or labeled angry. Or lonely. Or difficult. We're robbed of our agency to do and be anything that's outside of the boundaries of whatever is perceived as normal. (Allen 2016)

Allen's self-examination represented a moment of clarity, a shift in consciousness, and a problematizing of the familiar parameters of the egg freezing debate. Rather than pondering whether egg freezing allows women to keep up with men in the workplace, as many feminist bioethicists have done, Allen asked whether women of color were even being informed of the option of egg freezing or, if given the option, whether they felt free to take it without experiencing stigmatizing repercussions based specifically on race. In other words, Allen's piece had the effect of illuminating what it might look like to "decenter" whiteness in a bioethical analysis of egg freezing.

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I begin this paper with a brief reference to Reniqua Allen's op-ed because I believe the moment is ripe for asking how much progress has been made in decentering whiteness in bioethics. Nearly 20 years ago, Susan Wolf, professor of law, medicine, and public policy at the University of Minnesota, diagnosed what was missing in bioethics: "[A] bioethics analysis that places race, ethnicity, and gender at the center" (Wolf 1999: 66). In her judgment, bioethics had, to its detriment, "held fast to its liberal roots, condemning discrimination and calling for equal treatment but failing to dig deeper into the…debates about difference" (66). Wolf felt the integrity of the field was at stake and specified the harms resulting from a failure to change course. She wrote: "[T]he damage done by a bioethics that erases difference occurs on a number of levels. Individual cases are wrongly construed, entire patterns of profound harm are left unchallenged, bioethics itself becomes complicit in those harms, and the field devolves into a bioethics by and for those who least need it—the already dominant. It is small wonder that the field has remained alarmingly white and nondiverse" (71).

Since Wolf wrote those words, significant strides have been made in placing gender at the center of bioethical analysis. However, one could easily argue that not enough work has been done to put race at the center of bioethical analysis, including feminist bioethical analysis. Scholars such as philosopher Camisha Russell (2016) and historian John Hoberman (2016) have assessed the degree to which the bioethics literature has focused on race. Hoberman, for example, surveyed the articles in major journals of bioethics that focused on race over the 15-year period from 2001 to 2016 and found only a few substantive examples. Russell's examination found that even when race was addressed, its presence did not have a fundamental impact on the theoretical work produced by philosophical bioethicists.

My intention here is not to reiterate the findings of Russell and Hoberman, or other general assessments of bioethics, but to focus my discussion more narrowly on the field of *feminist* bioethics. By using assisted reproductive technologies (ART) as an illustrative case, I hope to suggest what decentering whiteness might substantively look like and, by doing so, demonstrate why decentering whiteness is so critically important to the field of feminist bioethics. I argue that feminist bioethics needs to put race at the center of analysis, by which I mean it needs to embrace a shift in thinking that fundamentally alters what gets labeled as a problem and defined as a solution. This change cannot be superficial, self-serving, or transitory but should reach to the very core of what "feminism" is.

Identifying the Problem: Disparities in ART Use and Outcomes

What does it look like to consider assisted reproductive technologies (ART) with race at the center of analysis? One strategy is empirical: to look simply at who has access to ART. Surveys of ART usage show significant differences in access to ART by race and ethnicity (Quinn and Fujimoto 2016). Whites use a disproportionately large share of infertility services, given their overall population in the United States, while African-American and Hispanic women use a disproportionately small share of infertility services, given their numbers in the general US population.

For example, blacks were 12.9% of US general population in the year 2000, while whites were 75.1% of US general population (Seifer et al. 2008: 1707). However, only 3666 or 4.6% of ART cycles were undertaken by black women, while 68,607 or 85.4% of ART cycles were undertaken by white women (Seifer: 1707). Notably, white women with higher levels of education and socioeconomic status are the most likely to access infertility care, even in states where insurance coverage for infertility treatment is mandated and theoretically more widely available. The state of Massachusetts, for example, which mandates insurance coverage for infertility treatment, provides a particularly stark set of contrasts:

> [I]n Massachusetts, only 3.9% of infertility patients were Hispanic/Latino, compared with 6.8% of the state population being Hispanic/Latino. Furthermore, none of the infertility patients had less than a high school diploma, compared with 15.1% of the state population, and 49.6% of infertility patients had advanced degrees, compared with 12.4% in the state. Finally more than 60% of infertility patients had an annual household income above $100,000 compared with only 17.7% of the state's population. (Quinn and Fujimoto 2016: 1121)

Clearly, infertility services, including ART, represent an elite medical consumer item that is not broadly or equally accessible.

One of the most widely cited studies in recent years examined the utilization of ART in the "equal access setting" of a military base—in this case the Walter Reed Army Medical Center—where ability to pay was a nonissue. Remarkably, "African-American women utilized ART services at a fourfold greater rate than [they did] in the U.S. ART population" (Feinberg et al. 2006: 893). Overall, black and white utilization rates of ART were proportional to the actual population of these groups in the US military. Specifically, whites were 64.2% of the total military population and 66.9% of the users of ART at Walter Reed Army Medical Center; blacks were 19.1% of the total military population and 17.4% of the users of ART at Walter Reed Army Medical Center (Feinberg: 890). Interestingly, Hispanics still underutilized ART at Walter Reed compared to their total population in the US military, but researchers did not offer an explanation for this disparity. Although limited in scope, this study suggests that removing the factor of socioeconomic inequality would partly reduce the inequality of access to ART.

In addition to charting the phenomenon of disparate access, this study and several others have also pursued the question of disparate outcomes: why there appears to be a racial disparity in how well women do with ART when they use it. The most obvious indicator of success with an ART cycle is whether it results in a live birth, but outcomes are also measured and compared according to clinical pregnancy rates, implantation rates, and spontaneous abortion rates. Data about disparate outcomes according to race are not conclusive. Not all studies agree that racial differences in outcomes are statistically significant. However, where differences are noted, nonwhite women seem to fare worse. For example, studies have found that leiomyomas (uterine fibroids) are linked with lower live birth rates after ART and that African-American women seeking infertility treatment tend to have more uterine fibroids (Seifer et al. 2008; Quinn and Fujimoto 2016). Data show that African-American women tend to endure more months of infertility compared with whites before seeking treatment (Seifer: 1706). Delays in seeking treatment may decrease the probability of success. A separate study found that premature progesterone elevation on the last day of ART stimulation is linked with lower live birth rates after ART and that nonwhite women seeking infertility treatment are more likely to have premature progesterone elevation (Hill et al. 2017: 159). Unfortunately, these studies do not address the causes of these underlying health issues or why certain groups of women are more likely to have them, leaving many questions unanswered.

Looking for an explanation for racial disparities in ART outcomes is complicated. The search begins on shaky ground because the initial categorization of patients by race is not firm. Many clinics actually do not report the race/ethnicity of their patients undergoing IVF cycles (Wellons et al. 2012). A systematic review of Society for Assisted Reproductive Technology (SART) Clinic Outcome Reporting System (CORS) data from 1999 to 2007 found that "more than 35% of cycles could not be used for comparisons of racial/ethnic groups and reproductive outcomes because the data on race/ethnicity were indeterminate" (Wellons: 407). Thus, incomplete information undermines the reliability of claims of racial disparity.

In addition to the indeterminacy of how clinics categorize their patients, there is a more fundamental question about the ambiguity of race itself. Legal scholar Dorothy Roberts's claim that it is counterproductive to seek "biological explanations for social problems" is relevant here (Roberts 2014: 1779). Race is not a natural or biological category but rather a socially constructed one. As such, it might be more accurate to talk about "health inequities" rather than "health disparities," to use Roberts's preferred wording, because differences in a health are so often the "result of unjust distribution of social, economic, political, and environmental conditions" (Roberts 2012: 333). For Roberts, the point of highlighting racial disparities in medical outcomes is not to point back to race itself as a cause but to raise our awareness about social inequality as the root cause of poorer health outcomes. Indeed, some studies even suggest that racial disparities in health may be the product of racism itself. For example, "[F]oreign-born non-whites [in the United States] have better health outcomes than their U.S.-born counterparts—outcomes that decline the longer the non-white person lives in the U.S." (Russell: 48).[1]

For their part, scientific researchers who seek explanations for racial disparities in ART outcomes generally seem open to the possibility that these disparities could be the result of "biologic differences":

> Although access to care differs for whites and racial minorities, it is unclear if IVF outcomes vary as a result of biologic differences with a host of other contributing factors, or if these outcomes truly represent a disparity in medical care. Of course, any study of racial and ethnic variation is complicated by social, cultural, nutritional, environmental, physical, metabolic, and genetic confounders. (Quinn and Fujimoto 2016: 1122–23)

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[1] Russell is citing the work of Thomas LaVeist. 2005. *Minority Populations and Health: An Introduction to Health Disparities in the United States*. San Francisco: Jossey-Bass.

Identifying confounding variables and getting to the bottom of true causes seem exceedingly complex. However, as Roberts suggests, the search for biological explanations may not be as helpful as a more thorough-going investigation of the social context surrounding ART use, including the "unjust distribution of social, economic, political, and environmental conditions" (333).

To be clear, the Walther Reed Army Medical Center study provides an encouraging example of what can happen when one factor of inequality—the inability to pay—is removed from the equation. It is not surprising to learn that reducing economic barriers would lead African-American women to use ART in equally proportionate numbers to whites. However, other types of barriers yet to be explored must still be in play if not all ethnic groups began using ART at Walter Reed in numbers proportional to their population. In addition, research that seeks to identify racial disparities in ART outcomes and pinpoint their causes is commendable insofar as its underlying motivation is to enable better ART outcomes for everyone. However, such research may be limited in what it truly illuminates.

Merely pointing out disparities in ART access and outcomes may not go far enough toward decentering whiteness in bioethical analysis in this case. Calling for equal treatment may not go far enough in interrogating the assumption that the white experience is the normative experience while everything else is a deviation from that norm. As Camisha Russell writes, "It is not simply a matter of applying bioethical analysis to the problems of marginalized people (to 'help them out' or 'be more fair'). Rather it is a matter of making bioethics more genuinely universal in its scope by gathering more perspectives…as a means of obtaining a more comprehensive (and more just) view of the world" (Russel: 49).

Problematizing the Center: "Lean-In" Feminism and the Unified Sisterhood Fantasy

How else could we look at assisted reproductive technologies in a way that would decenter whiteness? In an article entitled, "Differences from Somewhere: The Normativity of Whiteness in Bioethics in the United States," bioethicist Catherine Myser argues that:

> The dominant white center must be problematized, displaced, and relocated for diversity work to make a difference in determining what counts as an ethical issue and to adjust or revise dominant bioethics values (e.g., hyper individualism and truthtelling) and concepts (e.g. autonomy) (Myser 2013: 7).

Bioethics has been rightly criticized for mistaking the white experience as the universal experience (Wolf 1999: 71). For its part, feminism has also been rightly criticized for mistaking the white experience as universal (Hull et al. 1982; Crenshaw 1991; Harding 2004). In Sandra Harding's words, "Feminism has a long history of association with bourgeois Liberal rights movements, racially and ethnically discriminatory projects, heteronormative understandings, and other theoretical luxuries available to women from the dominant groups" (9). But white experience is as particular, biased, and subjective as any other. A white perspective is not a neutral, objective perspective. White cultural values have their own normative content (DiAngelo 2017).

Given their disproportionate use by white women, assisted reproductive technologies (ART) in general—and perhaps social egg freezing most pointedly—provide an opportunity to discuss the particularity of these white values and problematize this dominant white center. I single out social egg freezing for closer examination in this paper largely because it is a special case of ART, one done for "elective" rather than "medical" reasons and one aimed at preempting or circumventing age-related fertility decline rather than actually treating infertility in the moment. Social egg freezing is an "extreme" case of ART in that epitomizes in a dramatic way some of the most common assumptions about the values that motivate its use. The decline of women's fertility after age 35 is a biological reality. Delayed childbearing is a social reality. How will women who want to have children in today's world make it work? Although data on who uses egg freezing are much more limited than data about ART generally, the marketing for social egg freezing in the United States is explicit, enterprising, and revealing. The targeted consumer is almost always white and affluent. Likewise, the abundant popular media discussion of social egg freezing reveals some of the assumptions at work.

What are some of the values that seem to drive egg freezing? In one interpretation, social egg freezing assumes a time-limited "race" for marriage, parenthood, education, career, and social status. The legitimacy of all facets of this race is presumed; egg freezing provides a way for women to stay in the game. Egg freezing assumes life plans are driven by consumer preferences and individual choices. Egg freezing does not require a restructuring of society to make it easier to combine employment with childbearing. It does not seek fundamental change. It enables privileged women to access more privilege. It assumes financial plenitude rather than scarcity. It assumes that biogenetic ties (and racially homogeneous ties) are valuable and worth the considerable expense. To follow this interpretation to its logical conclusion, egg freezing is an application of the "lean in" advice Sheryl Sandberg offers to the ambitious and talented (Sandberg 2013). More specifically, it is the application of a "lean in" model of feminism to the problem of the biological clock: be proactive, preempt age-related fertility decline, keep your options open, and stay at the table.

In addition, the attention given to the elite experience of egg freezing reveals how "what counts" as an important issue of reproductive healthcare may be skewed by the dominant white center. Inadequate access to basic health services like preventative screenings, prenatal care, birth control, and abortion and political threats to these basic services arguably deserve more attention than egg freezing. These issues certainly affect more people. However, the feminist bioethical analysis of egg freezing has not generally conceptualized or critiqued it in ways that have traveled very far outside this individualistic frame. White bioethicists/white feminists have asked: will egg freezing provide greater autonomy or not (Harwood 2009)? Will it be a form of affirmative action in the workplace or not (Goold and Savulescu 2009)?

These questions assume that the ultimate goal of gender equality is equality with (white) men in the (white) workplace. The goal of healthy (white) babies is perhaps also assumed, if unstated.

But as black feminists have been arguing for decades, and as should be abundantly clear after the 2016 US presidential election, whiteness is not representative of all experience. As aptly stated in this post-mortem of the 2016 election: "For many women of color, white feminism feels less like a unified fight for the liberation of all women, and more like a campaign to ensure white women have the same status, rights and privileges as white men, and thus the corresponding power to oppress black and brown people" (Lasha 2016). Ninety-four percent of black women voted for the female candidate for president, Hillary Clinton. The majority of white women voted for now President Trump (Rogers 2016). One of the lessons of that historical moment was the thorough debunking of the myth that white women would vote for women's interests generally. What we saw instead, in the case of white women, was race and class interests trumping gender.

Here I would pause to emphasize the obvious: that the myth of a unified sisterhood has been a problem for feminism for a very long time, at least since the days of the American suffrage movement, if not before. Simone de Beauvoir's observation in 1949 remains just as true today: "As bourgeois women, they are in solidarity with bourgeois men and not with women proletarians; as white women, they are in solidarity with white men and not with black women" (de Beauvoir 2011: 8). The stereotypical white woman's experience of infertility, ART, and egg freezing, as sketched above, is just that: a stereotype. It does not represent all women's experiences. It is not the basis of a unified solidarity of women's interests. It is not the basis for universal pronouncements from bioethicists about "generic" patients.

All of this brings me back to the perspective of one particular person of color: Reniqua Allen, the op-ed author quoted at the outset who was considering freezing her eggs. Allen worries about her decision in ways that would not burden a "typical" white woman. She writes:

> Considering this procedure opens up the possibility that I could become a single mom as a black woman. I worried about becoming a stereotype, a stigma, despite coming from a loving, stable, middle-class single-parent home myself. (Allen 2016)

Notably, a recent study of women who froze their eggs for nonmedical reasons found that the top reason for not using frozen eggs to become pregnant was not wanting to become a single parent (Hammarberg et al. 2017: 579). In fact, 41% of the women surveyed chose "do not want to be a single parent" as the reason for not using stored eggs (more than any other reason). The study, conducted in Australia, did not indicate the racial or ethnic identity of the respondents. Demographic data were collected for the respondents' age, relationship status, level of education, occupation, and private insurance status, but not race. Are we to assume that race is irrelevant and/or that the respondents were all white? It would be a false equivalence to say that Allen's fear of being a stigmatized black mother in the United States is the same as these women's aversion to becoming single parents in Australia. There is no generic patient-consumer of egg freezing, only the situated experience of particular individuals.

Reniqua Allen sees herself as an individual choosing and at the same time identifies as a member of a group whose choices have been curtailed and criticized. She writes:

> It felt like my community had been left behind in this new path to maternal "empowerment" that centers on elite white women, who have long been thought of as the model of femininity and motherhood (Allen 2016).

The "lean in" empowerment message is not lost on Allen, but she recognizes it does not apply to her. The advertisements she sees feature white women and white babies. The clientele of the clinic is almost entirely white.

In addition, Allen perceives racial discrimination as transcending class boundaries. Whether poor or middle class, black women's reproductive choices are not respected, including the choice to subordinate having a baby to other life goals:

> Poor black women are criticized for having too many babies they "can't afford" and professional middle-class black women are criticized for being too picky and not finding a man. But when professional white women follow these same patterns, it's often labeled a trend or brave or empowering (Allen 2016).

Allen is writing here about personal experiences and perception, but she is also referencing the power of cultural approval or condemnation. "Who gets to be a 'legitimate' mother in the United States?" (Ross and Solinger 2017: 3). Interestingly, contrary to the common narrative, recent studies suggest that delayed childbearing may not actually be due to the prioritization of professional goals but simply the lack of a suitable partner. According to the authors of the study from Australia:

> Although the increasing age of childbearing observed in most high-income countries is often framed as a result of women electing to pursue other life goals before having children, evidence suggests that the main reason for women having children later in life is the lack of a partner willing to commit to parenthood (Hammarberg et al. 2017: 579).

This news—this superficial commonality among unpartnered women—might be cold comfort to Allen, who experiences a racially specific inhibition and anticipates a racially specific stigma.

Allen describes her visit to a New York fertility clinic and shares her thoughts upon seeing only one other black woman in the crowded waiting room. She wonders to herself, "Did [this woman] have concerns about stigma? Lingering worry about the history of black women and forced sterility treatments…? Fear that she would be seen, negatively, as a 'baby mama?'" (Allen 2016). She makes no assumptions about the experiences and perception of this other woman, and even refrains from speaking to her, writing, "[R]acial solidarity today can be a tricky thing, valuable to some and a disdainful reminder of the past to others" (Allen 2016).

Allen's self-examination demonstrates there is no neutral space from which to consider using egg freezing. Individual acts of reproductive autonomy are not unfettered acts of the will but take place within a complicated social context. Her concluding thoughts express hope for the possibility of true freedom of choice and a thorough revision of norms: "I want black women to feel like egg freezing isn't just for their rich, white peers and to know that we, too, can make unconventional decisions the norm" (Allen 2016).

This extended examination of one woman's perspective helps to problematize the dominant white center because it brings specificity and particularity to the discussion of ART. This one individual author is asking for specific changes: better information about reproductive options, inclusion in the marketing for egg freezing, inclusion in physician's consideration of who counts as a legitimate candidate for egg freezing, more freedom in decision-making, freedom from stigma, and more. Her experiences and perceptions help to displace the white experience as the normative experience, they displace the idea that there is generic patient in bioethical analysis, and they "make a difference in determining what counts as an ethical issue" (Myser 2013: 7).

Decentering Whiteness as an Ongoing Responsibility of Feminist Bioethics

I would like to make three points about what I see as the ongoing responsibility of feminist bioethics to decenter whiteness in its analysis, following up on my earlier claim that not enough work has been done. First, decentering whiteness requires a consideration of epistemic limits and privilege, including the epistemic advantage of what has been called "insider-outsider" status. Second, decentering whiteness in feminist bioethical analysis requires a questioning and broadening of the goals of feminism itself, including questioning the conceptualization of equality as equality with white men and advocating for reproductive justice that ends oppression for all. And finally, decentering whiteness calls for an embrace of empathy in service of a more responsive and flexible worldview.

The Epistemic Advantage of "Insider-Outsider" Status

Moving race from margin to center, in the famous words of Bell Hooks (1984), and thus perceiving reality more clearly, requires a consideration of epistemic limits and privilege. Decades of controversy have dogged feminist standpoint theory because critics fear that it implies both essentialism (i.e., that all members occupying a certain "standpoint" or social location see and know in exactly the same way) and automatic epistemic privilege (i.e., by virtue of one's social location or membership in a particular disadvantaged group, one automatically has superior knowledge) (Wylie 2003: 28). But the project of decentering whiteness need not fall victim to these critiques of standpoint theory, in part because the critiques have been answered with refinements of the theory.

For example, the insights of feminist standpoint theory have been refined by the insights of intersectionality (Crenshaw 1991). All of us stand at the intersection of multiple identities, to summarize the most basic starting point of intersectional feminism. Greater awareness of the multifaceted nature of our identities decreases the temptation to "essentialize"—because we know to look only at someone's gender, or only at someone's race or class, will ignore the points of intersection of gender, race, and class. This greater awareness encourages us to value the perspective of an individual person like Reniqua Allen without "essentializing" her experience or making it stand in for the experiences of all African-American women. Allen's story has complexity and meaning, and it is her story to tell.

Although claims of automatic and all-encompassing epistemic privilege may be indefensible, feminist philosophers have satisfactorily defended the idea that some epistemic advantage is possible. One of the most basic premises of feminist standpoint theory is that "the social identity and position of inquirers themselves can be relevant to inquiry produced" (Roth 2016: 29). That is not to say that one's social identity is wholly determinative, only relevant. Amanda Roth, drawing on Alison Wylie (2003), has argued that having an "insider-outsider" status can be especially illuminating. "Insider-outsider" status refers to the ability to travel back and forth between center and margin, to perceive and understand both the cultural cues of a dominant group and those of marginalized group. Somebody like Reniqua Allen, who is both a professional woman and also a member of racial minority, experiences both margin and center, both inside and outside the dominant culture, and therefore sees more and sees differently than the person who is only one or the other. Some call this epistemic superiority. I am happy to call it epistemic advantage.

To let the call for decentering whiteness be sidetracked or sidelined by concerns about essentialism is already to discredit the call for decentering before one has done any of the work. To let the call for decentering whiteness be defeated by objections that some people are claiming better insight and knowledge by virtue of the complexity of the social worlds they inhabit is similarly to abandon the effort without adequate justification. It is to forfeit, out of fear and prejudice, the opportunity to recognize and respond fully to the unbalancing, the refocusing, the revising, and the disorienting changes that *necessarily* must accompany a displacement of the dominant center. In other words, the critiques of feminist standpoint theory are overblown and ultimately distract from the work of decentering whiteness.

As should be increasingly clear, the benefits of engaging in the project of decentering are significant, and the costs of not doing so are even greater. There is a great deal of intersectional work already being done by a number of well-established activist organizations like SisterSong, Fertility for Colored Girls, Black Women's Health Imperative, New Voices for Reproductive Justice (New Voices Pittsburgh), Colorado Organization for Latina Opportunity and Reproductive Rights (COLOR), and Native Youth Sexual Health Network, to name a few. These groups are defining for themselves what count as the most important priorities in women's reproductive health, and they are a source of advocacy and empowerment for many women of color.

Avoiding Conceptual Tokenism

Second, the project of decentering whiteness is not merely a reordering of priorities or treating race as an "add-on" to generic patients who are analyzed by generic principles. It is instead a more fundamental reconceptualization of how problems are defined and solved. To return to Camisha Russell:

> In the case of bioethics… I would argue that philosophers of race must insist upon not only the necessity, but also the *centrality*, of discussions of race to the broader field. They must show that there are vital lessons to be drawn from the experiences of racial minorities for bioethics *as a whole*. (Russell, 49)

This position is shared by African-American philosopher Charles Mills, who speaks more generally about the discipline of philosophy (not the sub-field of bioethics) in his work "Philosophy Raced, Philosophy Erased" (2012).[2] Mills emphatically rejects "conceptual tokenism," which he describes as a half-hearted effort to bring race into the core of one's analysis. Conceptual tokenism occurs when:

> [A] black perspective is included, but in a ghettoized way that makes no difference to the overall discursive logic of the discipline…in question: [including] the framing assumptions, dominant narratives, prototypical scenarios. (Mills 2012: 54)

His critique of conceptual tokenism is tied directly to his criticisms of philosophy:

> [T]he conception of the discipline [of philosophy] itself is inimical to the recognition of race. Philosophy is supposed to be abstracting away from the contingent, the corporeal, the temporal, the material, to get at necessary, spiritual, eternal, ideal truths. Because race as a topic is manifestly not one of those eternal truths… it is necessarily handicapped from the start… Philosophy aspires to the universal, whereas race is necessarily local, so that the unraced (whites) become the norm. (Mills, 60)

Susan Wolf made very similar arguments about bioethics as a field: that it has "strained for universals, ignoring the significance of groups and the importance of context," and in so doing has failed to interrogate racist assumptions (Wolf: 70).

I agree. Conceptual tokenism should be consciously avoided in bioethics. Feminist bioethics should redouble its efforts to put race at the center. But what does this mean for how ART or egg freezing should be fundamentally reconceptualized? Perhaps it means foregrounding the extent to which reproductive technologies reproduce social inequalities and the extent to which they reproduce whiteness itself. Perhaps it means foregrounding whose reproduction has been historically suppressed and whose has been encouraged and taking steps to amend past wrongs. Perhaps it means letting go of liberal, idealized notions of equality as equality with white men and embracing instead the goal of reproductive justice that ends oppression for all.

Reproductive justice, as comprehensively explained in a new book by activists Loretta Ross and Rickie Solinger (2017), is a broader, more inclusive frame than what has previously been known as (white) pro-choice feminism. Pro-choice feminism prioritizes reproductive freedom but starts from a position of rarely interrogated privilege. For example, in discussing the impact of the landmark US Supreme Court decision, *Griswold v. Connecticut*, Ross and Solinger explained that women on the margins did not really benefit the way affluent white women did:

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[2] Mills worries, for example, that his work, especially *The Racial Contract* (1997), has had no impact on mainstream (white) political philosophy. He has tried to bridge abstract discussions of justice and rights with a concrete political discussion of racism, which, he argues, is itself a political system.

> Achieving this privacy right—having what amounted to the "negative right" to be left alone—was not likely to help women without those resources. If you didn't have a private doctor, if you were poor, if you were African American, Mexican American, or Puerto Rican and the target of various forms of racism including population-control measures, then reproductive rights required much more clearly defined guarantees or "positive rights," beginning with a safe and healthy place to live with your family in a community free of the impacts of chronic racism, a living-wage job, and access to comprehensive public health services, including, if you chose, contraception. (Ross and Solinger 2017: 119)

The reproductive justice movement, now in its third decade, is a good example of the kind of questioning and broadening of the goals of feminism that must take place. Significantly, reproductive justice foregrounds the right to have children, not just the right to avoid having them. It is attentive to the history of coerced sterilization, for example, so that experience provides a vital lesson for the present. The goal becomes ending oppression for all, not enabling a few to leverage their privilege in the name of gender equality.

Transformative Empathy

Finally, empathy is both a crucial prerequisite for decentering whiteness and also a byproduct of decentering whiteness, but I mean empathy in a very particular way—not simply fellow feeling but a transformative connection that realigns and expands one's vision.

Some call feminism the radical notion that women are people and that a woman's experience is not peripheral, strange, other but is in and of itself a complete human experience of a real and whole person, whose perspective is wholly legitimate as it exists, however it was constructed. If that is true, then intersectional feminism intentionally expands this notion to everyone in the human community, with all of their multiple, intersecting identities: race, ethnicity, sexual identity, class, and more. If we take these radical notions seriously, then we have to let the perceptions of particular individuals like Reniqua Allen fully inhabit our field of vision. And then we must look for more people and more examples, in order to increase our knowledge and understanding of the varieties of human experience.

The goal is not to minimize the particularities of human experience or to construct from them false universals but to allow the particularities of individual human beings to facilitate true empathy. It is forging the connection across difference that should be the focus of energy in philosophy, bioethics, and feminist bioethics.

As Patricia Hill Collins has explained, the goal is not separate, dueling worldviews, but rather distinct contributions to an inclusive humanist vision (Hill Collins 1990). Decentering whiteness is an inductive project that leads to the formulation of new values. Or in the words of Camisha Russell: "We must go beyond simply adding some attention to the problems lying at the margins of bioethics; we must look from the margins to the center in favor of something more expansive, more responsible, more respons*ive*, and much more flexible in terms of its worldview" (Russell: 49).

Conclusion

Raising awareness about the limitations of feminist bioethics, important though this work may be, is only a preliminary step. The deeper question for further consideration is whether the field we call “feminist bioethics” should really be renamed “white feminist bioethics” or whether it is possible to realize Patricia Hill Collins’s inclusive humanist vision, which would be built on a much more diverse range of voices and perspectives. This paper has only attempted to contribute to the first, preliminary step by calling attention to the limitations of feminist bioethics in the case of ART. Notably, it has been an exercise in self-reflection, as my own previous writing on egg freezing has placed it squarely within the framework of reproductive choice and autonomy.

White feminism/white feminist bioethics needs to examine the ways in which it has perpetuated the oppression of people of color in its single-minded pursuit of the goal of equality with men in the workplace, in parenting choices, and in society generally. Decentering whiteness changes the conversation, changes the identification of the problem, and changes what looks like a solution. The goal becomes instead ending oppression for all, not expanding or hoarding privilege. The more often voices like Reniqua Allen’s can command attention and take center stage, the more likely feminist bioethics will remain vital and relevant in the twenty-first century.

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New Pitchforks and Furtive Nature

Daniel P. Maher

> Naturam expelles furca, tamen usque recurret, et mala perrumpet furtim fastidia victrix.
>
> You may throw nature out with a pitchfork, and yet she will come back, and she will furtively break through your evil contempt, the victress. Horace, *Epistles*, 1.x.24–25 (Kirkland 1893)[1]

My title references a somewhat famous quotation from the Roman poet Horace: "You may throw nature out with a pitchfork, and yet she will come back, and she will furtively break through your evil contempt, the victress." In less contentious terms, Aristotle grants nature a similar priority by saying that art imitates nature and tends to complete what nature fails to finish. In his view, the art of medicine itself arises in order to compensate for nature's inability to produce or maintain health without intervention. If nature always achieved its end, there would be no need for such art. In our attempts to complete what nature begins, we presuppose that we know adequately what nature is doing and where we stand as deliberate agents in relation to sub-rational natural processes. In reproductive medicine in particular, artful innovations affect people in aspects of human life that are somehow natural and familiar: sexual attraction, the disposition to bond in pairs, the desire for and attachment to children who come to be from our own bodies, and, pervading these other dimensions, human mortality. All of this is both natural and familiar and, simultaneously, elusive and not completely understood by us. Familiarity permits us to overlook what nature really is and to think about innovations only or primarily with reference to how they expand our power or eliminate some risk. We take for granted the goal of extending our control over the generation of new human life, and we tend to forget about nature as we, in some cases, supplant it rather than complete it.

I am not claiming we should not do this, but only that understanding the meaning of what we are doing requires us to think again about the nature that

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[1] My translation.

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precedes our interventions. This proves harder than it looks because nature is furtive, or, as Heraclitus put it, “Nature loves to hide.” In fact, thinking about reproductive innovations illuminates what is hidden in plain sight and easily overlooked in nature. For example, the prospects of a child arising from a single “parent” through cloning or from three parents through mitochondrial donation[2] might lead us to ask for the first time what it means for human beings to arise naturally from two. In ordinary circumstances, people take for granted that we do not appear by parthenogenesis, but they do not question whether that means anything humanly significant. Again, the possibilities for mixing DNA from different species, decried by some as unnatural, invite us to think about whether nature as a whole has not been rather promiscuous in its readiness to shuffle DNA through the course of evolution. Nature is not unambiguous—I underline this because I say it only once—but our innovations in our own nature and its manner of preserving itself for the past several thousand years presuppose nature’s priority. This does not mean that we understand nature first in time, before we understand art and other human innovations. In this paper, I am concerned only with the hermeneutic or epistemological priority of nature, which derives from the fact that nature got here first. We can innovate only in a context established beforehand. The primum non nocere injunction urges us to avoid harming the existing order, and I am arguing that before we determine whether an innovation harms, we need to understand what it means by considering how it alters what is already present. On its own, nature can be rather quiet, and even silent or secretive. Our attention to nature is heightened and perhaps awakened for the first time, when we entertain a proposed innovation. Finally, I am not making claims that nature serves as a moral standard for our artful interventions. To the contrary, any attempt to make such an argument must come fully to terms with the furtiveness of nature.

Preliminary Distinctions

At the outset, we should note a superficial connection between the new and the old. We call things *new* in relation to something already present. The new is new by virtue of its difference from what came first and had once been new until, by virtue of the arrival of the new new, the once-new becomes old. To be new requires contrast with what came before. To speak of new ideas and innovations, then, as does this conference, is to speak with a time stamp and with reference to the immediate past. All of this is analytically true and not particularly noteworthy, except insofar as we tend to overlook it. There is a backward-looking temporal reference in everything called *new*.

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[2] I use this short formula (despite its imprecision) to name maternal spindle transfer and pronuclear transfer.

Beyond this relatively trivial attachment of the new to the old, we should note, secondly, that when we try to understand the meaning of something new, we appeal to what came before. Innovations are naturally understood in relation to what preceded, and this is true whether we generally regard the new and unfamiliar with suspicion or we eagerly embrace it as fresh and enlivening. We no longer call automobiles *horseless carriages*, but the formula expresses my point. We cannot but think that a new mode of doing something is a modified version of the old way. The old way has priority in our understanding because calling something *new* implicitly tethers it to something correlatively old and acknowledges the primacy of what got there first. This is no less true in the context of medical innovations. In an introductory comment about reproductive ethics, Carson Strong (1997) notes, “Feminist writers are concerned about whether advances in reproductive technology will increase or decrease the control that women have over their bodies and lives.” Here we understand innovations in view of their impact on existing relations of power. Moreover, although Strong asserted this at a particular time and with reference to a particular context, it remains true in our context, and it will be so in tomorrow’s context. Each successive advance stands in an analogous relation to its circumstances.

At this point, I turn more specifically to reproductive innovations and to my main concern. Artificial insemination (AI) was first attempted around 1860.[3] AI, as its name expresses, is the artificial version of something natural. At an elementary level, AI replaces a human action between Jack and Jill with an action performed by medical personnel. Today, it might involve freezing, washing, and other techniques that, in various ways, alter AI further, but even now its essential meaning comes from its contrast with natural insemination. About 20 years after the first attempts at AI, a significant innovation appeared in the form of artificial insemination by donor (AID). This is not a technical innovation, but an innovation in what the medical procedure means in the lives of people who undergo it. When we consider this innovation, the artificiality of things may be taken more or less for granted and emphasis then falls on what is new in it, namely, use of semen from a man who is not the woman’s husband. Unsurprisingly, some early critics spoke of AID as a form of adultery. Fatherhood is implicitly attributed to the donor rather than the husband; almost nobody thinks the technician performing the insemination deserves to be called a parent. This ignores the technician’s indispensable agency and focuses instead on the biological contribution of the donor, and yet the goal of AID is to make the couple parents. AID is more complex than AI.

Roughly a century later, Edwards and Steptoe gave us IVF and embryo transfer, and the meaning of this, again, appears with reference to what is new in it, namely, fertilization ex vivo. We might frame the question by asking whether the technician’s fertilizing an ovum in glass is significantly different from his fertilizing an ovum in the body. Does that difference make a difference?

I do not intend to try to give a complete answer to that question, but I would like to draw it out a little bit. In the celebrated case of Louise Brown, fertilization took

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[3] For the historical facts relating to AI and IVF in these paragraphs, I rely on Jonsen (1998).

place in vitro because it was not happening naturally. Whether we speak of infertility as pertaining to a couple or to an individual, IVF does not so much treat or resolve infertility as it compensates for infertility or bypasses it. The fallopian tube defect in Louise Brown's mother persisted even after she gave birth, and so we might say she remained, in a meaningful sense, infertile even though she gave birth. Having a second child would require again the services of her physicians.

The Priority of Nature

With this I come to my main point, which is that every new innovation in reproductive medicine should be understood not only in relation to earlier innovations but primarily in relation to the natural means of generating human life. This does not deny that today's innovations are necessarily related to yesterday's. In fact, one could envision a museum of assisted reproductive technologies displaying the genealogy of today's techniques arrayed in relation to less sophisticated and now obsolete interventions. And one would understand a great deal in this way. Nevertheless, I claim, the primary reference point for understanding each innovation remains the natural method for generating human life.

The clearest demonstration of this comes from the fact that those who innovate do not act exclusively upon the existing technology; they act primarily within the otherwise natural relation between Jack and Jill. Any innovative technique stands somewhere in the sequential or evolutionary development of reproductive technologies, but the family served does not stand within that sequence. In other words, even if we customarily think of reproductive medicine as a progressive enlargement of power to shape and control human fertility and as now far removed from the first, clumsy attempts at artificial insemination, Jack and Jill come to medicine almost directly from the state of nature, so to speak. They go from 0 to 60 in one office visit, and whatever contemporary techniques they encounter constitute innovations in their previously non-technological reproductive lives. In the case of a same-sex couple or even a single person seeking medical assistance to produce a child, the therapeutic options begin from the biological condition of the parties involved. While there may be no question of any organic infertility, generating a child will nevertheless require joining gametes and gestation in utero. Each person's circumstances permit involvement in this process in various ways. At an extreme remove, it would be technically possible for a single man to rely on donor semen, a donor egg, and a surrogate; even in this case, the technology manipulates the natural processes of other people's bodies and compensates for the natural infertility of a single man. A person or couple may desire a child, but, given their social circumstances, their bodies may not permit them to act on that desire without medical assistance. When they turn to medicine rather than to adoption agencies for a remedy, they involve themselves with the biology of reproduction. In each case, innovative reproductive technology takes the place of the natural way to generate babies, not the place of some outmoded technology. And so, the significance of each innovation lies not in its degree of departure from that older technology, but in its degree of departure from nature, that is, in the manner in which that innovation assists, replaces, or otherwise adjusts nature.

In making this assertion, I do not imagine I am discovering something unknown or endorsing something controversial. I am instead drawing attention to what is sometimes explicitly acknowledged but not, I think, sufficiently explored. In a widely reprinted article, Carson Strong (2004) considers the argument that cloning is not procreation because it does not involve uniting gametes. He writes, "To assess whether cloning in the infertility cases is procreation, we should compare it to the paradigm of procreation—what I shall call 'ordinary procreation'. I refer to the type of procreation in which a couple begets, by sexual intercourse, a child whom they then rear." Strong seems to regard this approach as obvious and not in need of any defense. I claim that Strong's approach, which recognizes nature's priority in establishing meaning, is necessary. For his part, Strong concludes that reproductive cloning is reasonably regarded as procreation, even though it involves some departures from the paradigm. Even after concluding this, we could still question whether reproductive cloning is good. We might even dispute whether Strong has understood the paradigm adequately while still agreeing that one needs to raise the question in this way. In other words, even if we agree to interpret new technologies in light of nature, we have not yet committed ourselves to any particular conclusion about the technology. That is, thinking about cloning in its likeness and unlikeness to nature as a paradigm does not determine one's answer to either question: Is it procreation? Is it something we should do?

Innovations in reproductive medicine have both a clinical and a technical side. For each patient or couple, the clinical significance of the innovation and its ability to provide relief are more important than the technical specifics of how this or that innovation may alter medical practice for physicians themselves. I take it for granted that medicine's immediate interest in technical innovation is essentially subordinated to the ultimate goal of responding to ordinary people who have no part in the history of medical innovation but who do have some trouble with their primitive means of generating babies. For those who are professionally involved in innovative reproductive medicine, there must be a strong temptation to think of one's work as consisting in modifying existing technology by making it more efficient or more powerful, as if one's primary goal were to produce something new for display in the museum I imagined. To take one's bearings instead by the natural relations of family life creates more problems and obscurity than it removes, for it is notoriously difficult to understand these natural relations and the sources from which they spring. Attempting to understand these dimensions of human life leads one to literature, philosophy, theology, and political theory as well as to biology, psychology, sociology, and anthropology. And there remains always the fact that we have no direct view of a pure human nature. Just as we cannot see human language without its being a particular, conventional language (such as English, French, Farsi, or what have you), so we never see human nature in its maturity except as it has been influenced and formed by a determinate cultural tradition, each of which includes elements that are nonnatural. Even if nature has one kind of temporal priority to convention, nature is not temporally first in our understanding. We must try to discover nature beneath the layers of custom and convention that shape and determine it for us. For this reason, any attempt to speak about what is natural for human families runs the risk of wrongly privileging as *natural* some particular conventional arrangement.

The Desire for Children

While acknowledging the obstacles to our understanding, I think we can clarify one important dimension of innovations in reproductive medicine by returning to Steptoe and Edwards. Unable to remedy the physical problem interfering with the Browns' fertility, Steptoe and Edwards managed instead to satisfy their desire for a child. When physicians act in this way, unless they understand themselves as in the business of using their knowledge of the body to satisfy whatever desires people bring them, the physicians must have some judgment that the desire they are satisfying is a good desire, that is, one that deserves to be satisfied through this or that medical intervention. And this raises some very difficult questions about what the desire for children is and in what circumstances it is good to satisfy that desire.

Surveys reveal a wide range of opinion among physicians on the questions of whether it is good to help, say, a single parent have a child or same-sex couples or couples past ordinary childbearing ages (Gurmankin et al. 2005). I want to argue that we inform and strengthen our opinions by examining them in light of an appeal to the natural order between parents and children. Obviously, again, opinions vary on how we ought to understand the natural order. To consider two views that lie at opposite poles, I note that some people see the division between the sexes as divinely ordained, while others consider it to be the unintended outcome of a long sequence of biochemical reactions governed only by a mixture of chance and necessity. On the first understanding, some interventions are understood to support the divine command to be fruitful and multiply, whereas others are understood to be nearly sacrilegious violations of our proper role in procreation. On the second understanding, the existing order has no particular claim to deserve to be conserved, and its goodness or badness might seem to be a function of the degree to which it matches our preferences. Given the vast differences between these two understandings and the conclusions to which they can be expected to lead, it may seem hopeless to begin here.

Instead of trying to identify at the outset, then, the ontological source of our sexual diversity and mechanism of generating new life, perhaps we can begin with the widespread and powerful desire for children as a recognizable aspect of our nature, whatever its source may be. People tend not to desire a child in general, but rather their own child, that is to say, a child generated from their own bodies. What this desire means is rather elusive. People sometimes interpret it as a wish that some subset of their DNA recur in the next generation. At best this could explain how human beings have understood themselves for the last couple of generations, but people desired children centuries before the discovery of DNA. Even today, most people know nothing specific about their DNA, and so it is rather silly to suppose that the real meaning of their desire for a child is a powerful urge to have half of their genes deposited in a younger human being. We do not love our genes, but the life we have through them. If we were after the proliferation of our genes, increasing body mass would seem to yield a more direct satisfaction. The desire to generate a new life has a human significance and not simply a genetic one. The meaning of reproductive medicine, in turn, depends on what it means to want children generated from one's own body with a complementary other. The pervasiveness and the strength of this desire, which seems to be constant (albeit not perfectly universal) despite many differences across cultures and times, make it possible for there to be careers in reproductive medicine, as distinct from careers in adoption services and kidnaping, which are also ways of acquiring children, although they are often thought to be less desirable methods in part because they lack the bodily connection.

In order to say something definite about what it means to generate children in the natural mode and still keep within manageable limits, I would like to concentrate on this notion of how children belong to parents. I have to say some things that everybody already knows, but I do so in order to draw attention to what is strange in the familiar. What exactly makes the child I father mine, and how does this relate to innovations in reproductive medicine? By nature, my child is not exactly *mine*, but rather *ours*. No human being is naturally fertile in isolation but only in combination with a complementary human being. And our possession of that fertility even in partnership with a second person remains tenuous in the sense that nature limits us to engaging in an action that might result in conception. We do not *make* a child in any ordinary sense; rather, we do something and accept the child we may happen to get. No child comes to be naturally as an individual isolated from others; each human being comes to be in a biologically determinate relation to two parents and, by extension, is located in relation to ancestors, siblings, and cousins. My child is less genetically like me than is my identical twin, and yet only my child is mine or, again, ours.

In becoming parents, there is naturally an enormous disproportion between our control over what we do and our lack of control over its possible consequence. In the ordinary case, Jack and Jill have the ability to select one another out from the crowd, and thus they exercise a certain indirect control over what traits might be found in any child they give rise to, but once they have selected each other, their capacity to control naturally the biological makeup of any child substantially ends. We do not normally require them to establish why the child is theirs, but we might need to give this some thought in light of two variations on this story in which we give answers that stand in tension with one another. A deadbeat dad is held to have failed in his moral and often legal responsibility toward *his* child despite the fact that he may never have had any voluntary intention of becoming a father. By contrast, a semen donor has intentionally acted so as to contribute to the generation of a child, and yet he often or normally has no parental responsibilities or rights.[4] In the one case we do and in the other we do not allow the man to construct by choice the

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[4] Due to natural differences, potential variations for women are more complex. A woman might be an egg donor, a genetic surrogate, or a gestational surrogate and yet not be expected or allowed to be a parent to the resulting child. For some recent studies of how family relations develop in these circumstances, see Imrie and Jadva (2014), Blake et al. (2016), and Carone et al. (2016).

meaning of his natural and biological relation to the child. The tension here suggests we may not have a consistent understanding of the relationship between the responsibility and right to parent, the scope of human choice, and the significance of genetic connection.

To illustrate this further, I cite a recent study (Lingiardi et al. 2016) that reported on interviews with 24 lesbian mothers about their understanding of parenthood and of the role of the sperm donor. "None of the mothers considered the donor to be their child's father."[5] In summarizing the attitudes of participants, the authors write: "When lesbian mothers planned to become parents there was no space for a third party involved in a parental role. . . . [H]is donation turned parenthood into double motherhood."[6] The study reports various ways in which the mothers tended to depersonalize the donor who is nonetheless essential to their motherhood. "The extent to which the donor was devalued and depersonalised was that he was just a genetic instrument to realise the mothers' will to have a child deriving from their union." Remarks like these express versions of attempting to throw out nature. The authors also report some ways in which the mothers' views shifted toward the donor and included gratitude, esteem, and acknowledgment that the donor had not only donated a body part but had made "the donation of life." They recognized also that the children, as they age, might reasonably want some more direct connection with that half of their biological ancestry. "It is like they put aside their fears and uncertainties and took into account the meaning to their child of being a donor's offspring." Remarks like these show nature working its way back in. The authors conclude:

> The present study promotes rethinking family configurations in the face of medically assisted procreation, shedding light on the complex interplay between parents' desire for their own child, fantasies about his or her entry into the world and the necessity of resorting to a third-party. . . . [F]emale-partnered mothers redefine the meaning of kinship and parenthood by foregrounding the intention to parent whilst reducing the importance of genetic linkages.

What they call "rethinking family configurations in the face of medically assisted procreation" is what I call acknowledging the priority of nature in relation to innovations in reproductive medicine. Our innovations require us to rethink the family. This kind of study illustrates how reproductive medicine leads us back to question again whether we know what it means to want and to have children.

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[5] On this issue Carone et al. (2016) report a similar attitude of gay men who are becoming parents through surrogate mothers: "When defining the surrogate's relation to the surrogacy child, no fathers intended her to be the mother, but all were aware that she would always be part of their lives." According to the studies mentioned in this and the previous note, those involved define that "part" variously, but the surrogates (or donors) are not construed as mothers or parents.

[6] In support of the basic thesis of this essay, I draw attention to the word *turned* in this sentence. By *donating* semen, the father has transformed himself into a nonparent and transformed the partner of the woman who carries the child into a mother. That is, the natural meaning that would otherwise obtain is transformed by human choice.

Innovations for Today and Tomorrow

The resistance to the notion of a three-parent family reported in that study raises the question of the significance of two parents. That is what we have by nature, but does it deserve to be preserved? I consider briefly two possible departures. First, let us consider mitochondrial donation, which is popularly described as yielding a three-parent child. The father of such a child is genetically related just as he would be to any child produced through IVF, but the mother has less genetic sameness with the child than occurs normally. Is the woman who supplies the healthy mitochondria more like a bone marrow donor than a gamete donor? Is that woman a parent? Whether we accept this procedure might be decided in terms of its safety, risks, and benefits, but what exactly does it mean to involve a third person who does not belong to the couple who desires to generate children together? I mentioned above how AID introduced a third party into AI as a substitute for one partner, but this innovation involves a third person in a completely new way. My argument here is that efforts to answer the question of what this innovation means must begin by considering what it normally means to belong to two parents.

And, second, what is the significance of replacing a child's connection to two ancestral lines with a connection to only one, such as would happen with reproductive cloning? This seems to be a much more disorienting action because the relationship between the clone source and the clone copy becomes completely opaque. The two might appear to be most similar to twins arising from a single fertilized ovum, which would make them like siblings. But if the source were an adult, say, a genome donor, would the clone copy belong as a child not to the donor's parents and not to the donor but to the person or persons who sought to have that genome cloned? One of the interesting things here is the complete separation of the generation of a living organism from any semblance of sexual activity between two parents. Having thrown that element of nature out, we seem to be able to define the relation between the clone source and the new life in any way we find convenient: sibling, child, or none at all. Does the clone copy stand in any natural relation of belonging to anyone else, or does the clone copy belong to anyone to whom he or she is assigned? Much of nature is thrown out here, but nature also breaks back in, for the clone copy will be fertile in the natural way as belonging to one of two complementary sexes.

Two things become unmistakable at this point. First, the person who would acquire and raise such a clone copy does something akin to adoption as distinct from generating a child out of his or her own body. Consequently, the meaning of this innovation, were it to occur, would be somewhat different from those interventions that aim to satisfy more familiar forms of the desire for children. Second, the person who acquires a clone to raise is rather far removed from accepting a child as constituted by nature and further along the road to choosing a child because it is expected to have specific traits. To be sure, other forms of selection based upon known qualities of embryos or gametes already occur in some existing forms of reproductive technology. One might argue that techniques for embryo screening and prenatal genetic diagnosis alter the relation between parents and children for the better precisely because they eliminate our passivity and our vulnerability to chance. My point here is only that these selection processes do in fact alter that natural relation and that we may not have recognized quite exactly what that means.

Having argued that we ought to examine our innovations with reference to what came before, I now look in the other direction and mention two authors who anticipate great innovations in the near future. Robert Sparrow (2013) published an article describing in vitro gametogenesis in which he raised the prospect of producing human embryos from gametes themselves produced in the laboratory. He refers to the elimination of the distinction between somatic and germ cells and the possibility of proceeding through several generations of embryos within the lab. To whom would such embryos belong? In other contexts, that degree of manipulation of biological material would probably qualify as patentable, and so one wonders whether the researchers themselves would not be best entitled to claim parenthood. Not that they would be likely to want it, but that wish is not enough to get the deadbeat dad off the hook. And that makes me wonder why we so readily discount the role of medical technicians in and, consequently, their responsibility for the generation of human life through existing technologies. There is a significant difference between someone who becomes a parent in the ordinary way and a technician who assists someone to become a parent, but we need to think more deeply about what that difference is and whether or how it is to be preserved.

Henry Greely's *The End of Sex and the Future of Human Reproduction* (2016) predicted that nature's union of sexual activity and the generation of human life is soon to end in technological divorce. Sex is to become purely recreational, and new life is to be produced in the labs. Perhaps he is right. I do not issue Brave New World-ish predictions or dystopian warnings. My point is rather more modest. However far our technological mastery takes us away from the natural way of making babies, that technology remains an alternative to or a substitute for nature's way. The primary reference point for understanding even tomorrow's innovations is not the once-new technology on which the latest new technology is the most recent variation; the primary reference point is ordinary human generation.

Conclusion

I have shown Carson Strong acknowledging this explicitly and others doing so implicitly. I have also argued that it is necessary for our thinking to proceed in this way, but that we do not do this seriously enough. In some cases, it seems that only some actual innovation (like CRISPR) or the anticipation that great innovation is imminent (like reproductive cloning) leads us to recognize the need to understand natural procreation. And our difficulty in cracking open such investigations often leaves us at first with little more to say than hackneyed clichés, such as "playing God" and "designer babies," which are somehow supposed to substitute for argument. And so we find ourselves surrounded by technological options that, I argue, we are not well-positioned to understand. Sometimes we proceed as if any procedure that results in a live birth were simply equivalent to nature's way of making babies, as if there were nothing to it other than mechanical combination of gametes, and as if we were free to construct the meanings of the relationships established however we find convenient. In some circumstances, we assume that genetic and bodily relationships matter more than human choice. We pay precious little attention to the desire at the heart of all of this, a desire so widespread and so powerful that it seems to deserve to be called a natural human desire, namely, the desire to generate new life out of one's own body.

Nature grants a way to satisfy this desire, and art supplements where nature fails. People will always disagree about what innovations are appropriate, but it seems incumbent upon medical professionals and those who set public policy to find a consistent approach. Before we evaluate innovations as good or bad, we ought to understand what they mean for beings like us. In order to see that, we must make the effort to understand what we are and do by nature, which is inescapably prior to what art accomplishes. Nature is prior always, or at least as long as our nature remains what it is. If the beings produced through future innovations retain within themselves the power to generate human life through a complementary other, a central part of our nature will be preserved in them no matter how we have generated them. If, by contrast, we produce beings who cannot generate life except through the lab, I am not sure what that would mean, but art would be prior to their nature in at least one sense. To consider how far different their nature would be from our own, we would have to try to know what place the power to generate life as we naturally do occupies in our nature. I do not think we understand that well enough even to deal with the real questions that confront us already.

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Assisted Reproductive Technology and the Proliferation of Parents: The More, the Merrier?

Greg Yanke

Introduction

Not long ago, Americans would often express their goal of having the perfect family consisting of a father, a mother, 2.5 kids, a dog, and a house with a white picket fence. The adage conveyed a past era's ideal family structure and concurrently suggested that it was unrealistic given the impossible aim of having 2.5 kids. Today, the reign of the nuclear family has ended. In 2013, less than half of US households consisted of biological parents and their offspring as compared to 73% in 1960 (Livingston 1998). Families with single, remarried, and same-sex parents have become prevalent.

Simultaneously, infertile couples and those who waited longer to start their families have taken advantage of advances in assisted reproductive technologies in order to have children. Sperm donors, egg donors, and surrogates have become increasingly involved in the reproductive process and occasionally play a continuing role in the resulting child's life. When more complex family units have subsequently fractured, courts were forced to resolve complicated parentage disputes. The zenith appeared to be the case of *Buzzanca v. Buzzanca*, 61 Cal.App.4th 1410, 72 Cal. Rptr.2d 280 (1998) in which the California courts grappled with determining who the parents of a child were whose conception involved two intended parents that contracted with a sperm donor, an egg donor, and a separate surrogate and then separated prior to birth. Although the potential five-parent family appeared to be an exceptional situation that was unlikely to reoccur, technology may make complicated parentage issues more commonplace in the future. We have recently witnessed the birth of a child with three genetic parents due to the pronuclear transfer from one woman's egg to another (Kolata 2016) and the advent of CRISPR (clustered regularly interspaced short palindromic repeats) technology that geneticists can utilize to edit the human genome in a simple, quick, inexpensive manner. Suddenly, we can use gene editing to produce a child with a large number of genetic parents

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that would each qualify as a potential parent under existing laws. Reproductive technology no longer limits the bounds of genetic parentage; it is now a matter of prudence and ethics.

In addition to the social and technological changes that challenge the traditional definition of the family, the law has altered the landscape as well. While drafters of the *Uniform Parentage Act* (2017) (the "UPA") have periodically amended its contents in order to reflect the fact that people are using assisted reproductive technologies more frequently, the Act has retained vestiges of the nuclear family ideal to the detriment of nontraditional families (Sroka 2013). However, with the Supreme Court's recognition of a right to same-sex marriage, state legislators will have to recognize the legal legitimacy of alternative conceptions of the family or face constitutional challenges that they will likely lose.

Are there limits to the structure of the multi-parent family? From a legal perspective, several American and Canadian jurisdictions now recognize that a child can have more than two parents. However, although other states and provinces may follow suit, it is unlikely that the Supreme Court would interpret the US Constitution as providing a right of citizens to have a multi-parent family structure. Thus, it will be up to individual states to determine whether nontraditional family structures should be legally recognized.

From an ethical perspective, although we should respect the autonomy of prospective parents in selecting the family structure that they deem appropriate, this must be subordinate to the principle of beneficence as it applies to the children of the relationship. Similarly, if we rely on a narrative analysis of the family, rather than bioethical principlism, to inform our moral deliberations, we will reach a comparable conclusion that places the children at the center of the determination.

Multi-parent Families and the Legal Landscape

The UPA stipulates how parental rights and obligations are to be determined in situations where the intended parents of a child utilize a sperm donor, an egg donor, and/or a gestational surrogate. As assisted reproductive technology has transformed, the Uniform Law Commission that drafts model legislation has amended the UPA. The latest UPA amendment occurred in 2017 in the wake of the 2015 case of *Obergefell v. Hodges*, 576 U.S. ____ (2015), in which the Supreme Court held that the 14th Amendment requires states to recognize same-sex marriage. The current version of the UPA now ensures the equal treatment of children of same-sex couples and removes gendered terminology from the prior version. The drafters of the UPA (2017) amendment acknowledge that after the *Obergefell* decision, "some parentage laws that treat same-sex couples differently than different-sex couples may be unconstitutional" (p. 1). They note a recent constitutional challenge to the Utah UPA, which provides parental rights to both members of a heterosexual couple that utilizes a sperm donor and surrogate but does not extend the same rights to both members of a similarly situated same-sex couple. In that case, *Roe v. Patton*, Case

No. 2:15-cv-00253-DB (D. Utah 2015), the court provided the same-sex couple with an injunction pending the hearing of their case and stated that the couple is "highly likely to succeed in their claim" (p. 1). Subsequently, Utah issued a revised birth certificate to the same-sex couple that listed both as parents and agreed to a permanent injunction, which essentially ended the case.

Though the UPA now recognizes same-sex couples, it maintains its limitation on granting legal status to a maximum of two parents per child. While the UPA acknowledges the parental rights of same-sex couples, it does not reflect the fact that a significant number of same-sex couples raise their children in multi-parent families that treat a third party, such as a sperm donor or a surrogate, as an additional parent (Bartlett 1984). Another limit of the UPA is that the Uniform Law Commission's model legislation constitutes recommended guidance for state legislators that is not binding on states unless they enact its provisions. States may ignore a uniform act, pass legislation that is identical to the act, or make any revisions that they deem fit. Though there are some uniform acts that every state has adopted, only Washington has adopted the 2017 version of the UPA since the Uniform Law Commission amended it so recently. However, the prospects for widespread state adoption of the 2017 UPA are dim given that only 11 states have enacted legislation that is identical or similar to the previous version of the UPA. As a result, potential parents in the country face a disparate patchwork of statutory and case law that has resulted in determinations of parentage that are contrary to the intentions of the parties involved in the assisted reproduction process.

Although the UPA does not recognize multi-parent families, some states and Canadian provinces have done so. In one of the most prominent cases, *Jacob v. Shultz-Jacob*, 923 A.2d 473 (2007) (PA. Super. Ct.), a same-sex female couple utilized a sperm donor for two children. The sperm donor was involved in the children's lives and helped support them financially. The court held that all three were legal parents of the two children. Similarly, in the Ontario case of *A.A. v. B.B.*, [2007] 278 D.L.R. (4th) 519, a same-sex female couple had a child with the aid of a sperm-donating friend. The couple's intention at the outset was to have the biological father be involved in the child's life even though they would be the primary caregivers. The non-gestational female of the couple wanted to adopt the child, but this could only be accomplished if the sperm donor relinquished his parental rights, which the couple did not want. Accordingly, the three adults applied to the court to have all of them recognized as legal parents. Despite the fact that the applicable legislation, the *Children's Law Reform Act* (1990), did not provide the court with the authority to make such a declaration, the court relied on the *parens patriae* doctrine, which gives it the right to protect those who are unable to act on their own behalf, to hold that the same-sex couple and the father were all legal parents of the child.

In addition to legal cases that have recognized multi-parent families, two North American jurisdictions have enacted statutes that permit a child to have more than two parents. California revised its *Family Code* provisions following a controversial decision in *In re M.C.,* 195 Cal.App.4th 197 (2011). In that case, the court confronted potential parental claims from three individuals. Two of the three, whom the court identified in the judgment as Melissa V. and Irene V., were in a volatile and abusive same-sex domestic partnership. During a period of separation, Melissa engaged in a relationship with Jesus Perez and became pregnant as a result. Melissa and Irene subsequently reconciled and got married in October 2008 after same-sex marriage became legal in California. Melissa gave birth to the child, which the court identified as “M.C.”, in March 2009. Although Melissa was the only person listed on M.C.’s birth certificate, Irene attended the birth and lived with Melissa and M.C. for almost a month until Melissa moved out of their residence. During the subsequent period, Perez sent funds to Melissa to help her care for M.C. After her involvement in an attempt to murder Irene, Melissa was incarcerated, and the state placed M.C. in foster care. Subsequently, the court was asked to determine who M.C.’s legal parents were. Under California law, Melissa was the legal mother of M.C., while Irene and Perez were each presumed parents because Irene was married to Melissa at the time of M.C.’s birth and Perez was the biological father. Although the court wished to declare that all three were legal parents of M.C., the law only allowed for a maximum of two parents. The court stated:

> We agree these issues are critical, and California’s existing statutory framework is ill-equipped to resolve them. But even if the extremely unusual factual circumstances of this unfortunate case made it an appropriate action in which to take on such complex practical, political and social matters, we would not be free to do so. Such important policy determinations, which will profoundly impact families, children and society, are best left to the Legislature. (p. 214).

In direct response to this judgment, the California legislature passed an amendment to the *Family Code* (§7612(c)) (Deering 2016) that provides:

> In an appropriate action, a court may find that more than two persons with a claim to parentage under this division are parents if the court finds that recognizing only two parents would be detrimental to the child. In determining detriment to the child, the court shall consider all relevant factors, including, but not limited to, the harm of removing the child from a stable placement with a parent who has fulfilled the child’s physical needs and the child’s psychological needs for care and affection, and who has assumed that role for a substantial period of time. A finding of detriment to the child does not require a finding of unfitness of any of the parents or persons with a claim to parentage.

This amendment applies the typical “best interests of the child” standard to the determination of parentage and only permits the recognition of more than two parents if finding otherwise would harm the child. The provision does not entail that any child will automatically have more than two parents or permit the court to give parental status to someone who does not qualify as an actual or presumed parent under existing law. While the amendment is often referred to as the “third parent law,” it does not limit the number of parents that a child could have.

Compared to the California provision, the law that provides for multiple parent recognition in the Canadian province of British Columbia is even more radical. Instead of merely providing a court with the jurisdiction to declare that a child has more than two parents, British Columbia’s *Family Law Act* (2011) allows potential parents to enter into an agreement to establish their multi-parent status prior to a child’s conception. Section 30 of the Act states:

30 (1) This section applies if there is a written agreement that:

(a) Is made before a child is conceived through assisted reproduction
(b) Is made between:
  (i) An intended parent or the intended parents and a potential birth mother who agrees to be a parent together with the intended parent or intended parents
  (ii) The potential birth mother, a person who is married to or in a marriage-like relationship with the potential birth mother, and a donor who agrees to be a parent together with the potential birth mother and a person married to or in a marriage-like relationship with the potential birth mother
(c) Provides that:
  (i) The potential birth mother will be the birth mother of a child conceived through assisted reproduction.
  (ii) On the child's birth, the parties to the agreement will be the parents of the child.

(2) On the birth of a child born as a result of assisted reproduction in the circumstances described in subsection (1), the child's parents are the parties to the agreement.

(3) If an agreement described in subsection (1) is made but, before a child is conceived, a party withdraws from the agreement or dies, the agreement is deemed to be revoked.

Section 30(1)(a)(i) and (ii) appear to limit the potential number of parents to three (i.e., the two intended parents and a surrogate in the first scenario and a married or common-law couple and a sperm or egg donor in the second scenario). However, it is likely that the court would interpret the section to include more parents since Subsection 28(3) of British Columbia's Interpretation Act (1996), which applies to all of its provincial legislation, states that "in an enactment words in the singular include the plural, and words in the plural include the singular." Thus, the word "donor" in Section 30 of the Family Law Act could include both a sperm donor and a separate egg donor. Moreover, it is possible that subsections 30(1)(a)(i) and (ii) are not be mutually exclusive so that one family could rely on both, which could result in two intended parents, a separate gestational mother and her spouse, a sperm donor, and an egg donor all being parents of one child. Thus, a child could have a maximum of three or six parents depending on how narrowly the courts construe the provision. To date, British Columbia courts have not interpreted Section 30.

While other American states may enact statutes or resolve cases in a manner that permits children to have more than two parents, a successful constitutional challenge to laws that limit the number of parents to two would permit multi-parent families in every US jurisdiction. While the findings in *Obergefell v. Hodges* and *Roe v. Patton* mentioned above suggest that parentage laws that treat heterosexual and same-sex couples differently will not withstand judicial scrutiny, it is less likely that those seeking legal recognition of multi-parent families will be successful.

Multi-parent cases do include issues that bear many similarities to those involved in same-sex marriage cases. In *Obergefell*, the court referred to four principles and traditions that supported the extension of marriage rights to same-sex couples: (1) personal choice regarding marriage being inherent in the concept of autonomy, (2) marriage supporting a two-person union unlike any other in society, (3) marriage safeguarding children and families through the permanence and stability of marriage, and (4) marriage being the keystone and foundation of the family. A proponent of multi-parent families would certainly assert similar autonomy interests and claim that the recognition of additional parents would likewise safeguard children in certain situations. However, in the 14th Amendment cases, the courts will only find a practice to constitute a fundamental right if it is "deeply rooted in the Nation's history and tradition" (*Moore v. City of East Cleveland*, 431 U.S. 494 (1977), p. 503).

Even though the history of marriage in the United States was exclusively heterosexual, same-sex couples in *Obergefell* and its companion cases were successful because they effectively framed the legal issue in terms of whether *marriage* was fundamental rather than whether *same-sex marriage* was fundamental. The Supreme Court explicitly rejected the latter issue, which allowed it to hold that the fundamental right to marriage applied to same-sex couples. Multi-parent families could have a similar avenue open to them since the Supreme Court has previously found that the sanctity of the family is fundamental (see, e.g., *Wisconsin v. Yoder*, 406 U.S. 205 (1972), *Ginsberg v. New York*, 390 U.S. 629 (1968), and *Griswold v. Connecticut*, 381 U.S. (1965)). To be successful, multi-parent families would have to frame the legal issue as whether the *family structure* is fundamental rather than whether *multi-parent family structures* are fundamental.

However, the Supreme Court has been hesitant to recognize nontraditional family units in the past. In the 1878 case of *Reynolds v. U.S.*, 98 U.S. 145 (1878), the defendant was indicted under a federal anti-bigamy statute for having multiple wives. He argued that this law violated his right to freely exercise his religious beliefs since he had a faith-based duty to practice polygamy. The Supreme Court confirmed that the First Amendment's free-exercise clause (i.e., "Congress shall make no law…prohibiting the free exercise thereof [i.e., of religion]") guaranteed religious freedom but found that although this constitutional provision encompassed religious opinion, it did not protect actions that violated social duties or undermined good order. The court further denied that polygamy was within the purview of the First Amendment since the practice "has always been odious among the northern and western nations of Europe" (p. 164). The Supreme Court reached a similar decision 12 years later in *Davis v. Beason*, 133 U.S. 333 (1890). Accordingly, parties wishing to achieve constitutional recognition of multi-parent families would have to distinguish their cases from those of polygamy. Arguably, the best way to accomplish this would be by emphasizing that, in certain situations, recognizing a multi-parent family would be in the best interests of the child. The courts did not address the possible existence of a child's fundamental right to a multi-parent family in the polygamy cases.

Multi-parent Families and the Ethical Landscape

Autonomy vs. Beneficence

"Best interests of the child" is a pervasive mantra in family law case decisions. The fact that this phrase is incorporated into Article 3 of the *United Nations Convention on the Rights of the Child* (UN General Assembly 1989) reflects its universality. It is an example of the bioethical principle of beneficence, which requires that an agent act in a manner that promotes the welfare of those that her decision affects. In the case of recognizing multi-parent families, beneficence competes with autonomy, the principle that an agent should be able to pursue a course of action that she chooses without interference. However, academics who have considered the propriety of permitting multi-parent families have emphasized beneficence (see, e.g., Appleton 2008; Bouchard 2007).

Those who have criticized the concept of multi-parent families have relied upon a variety of ethical arguments. They have suggested that it constitutes a war on traditional families; it subjects children to stigmatization; it can be used as a gender oppression tool; and it can exacerbate intrafamilial conflict. The traditional family argument was unsuccessful in the *Obergefell* case and is not especially compelling in the multi-parent family debate. The recognition of multiple parents in particular cases does not undermine the rights of those who wish to choose a nuclear family structure. Moreover, as discussed above, many alternatives to the traditional family already exist, including adoptive parents, same-sex couples, single-parent families, and stepparents, and there is no clear basis for suggesting that the nuclear family is relatively more stable or results in better consequences.

Even if children of multi-parent families are stigmatized because they are the product of an uncommon family structure, this is not a sufficient reason to prohibit the arrangement. After all, children of interracial marriages in America have been stigmatized due to societal prejudice, yet it would be unethical to suggest that this was a reason to prohibit the recognition of interracial marriage. Inappropriate stigmas disappear over time as people become accustomed to relationship structures that were once rare, such as the United States' increased acceptance of same-sex couples and children born as a result of assisted reproductive technologies. As Mianna Lotz (2012) maintains, "one highly efficacious way in which to de-stigmatize a given phenomenon is by precisely according it legal status" (p. 41).

Although Fiona Kelly (2004) endorses the recognition of multi-parent families, she has raised concerns that the ability of the courts to add additional parents to family units may serve as a tool of gender oppression. She worries that it might unwittingly provide courts with the power to "insert 'fathers' into lesbian families" given the historically gendered nature of family law (p. 171). This is a potential concern under the California framework since courts may declare a sperm donor to be a third parent in circumstances where doing so would be in the child's best interests. One could envision a scenario in which a married couple uses a known sperm donor that spends time with the child to an extent that a court might declare him a parent contrary to the married couple's intentions. The California law raises uncertainty in regard to how much interaction between a donor and a child is necessary to create a legal parent-child relationship. In contrast, the British Columbia law that requires a preconception agreement among all of the intended parents would not be subject to this worry.

The potential for the legal recognition of multi-parent families to increase intrafamilial conflict is arguably the greatest ethical concern. As the number of parents in a family increases, the potential for disputes does as well. In a society with a high divorce rate, the multi-parent family has the potential to disintegrate into a complicated custody battle in which a multitude of households strive for visitation rights and argue over child support obligations. Courts must then face the difficult task of maintaining numerous parent-child relationships while still providing the child with a stable environment. As Appleton (2008) notes, “When three (or more) parents are collaborating and the child is thriving, the case for multi-parentage becomes especially compelling,” but becomes “much more controversial upon the community’s dissolution” (p. 40). For those, such as Kelly (2014), who believe that the British Columbia legislation imposes unfair limitations on multi-parenting, such as restricting it to assisted reproductive technology cases, only recognizing biological or genetically linked parents, and requiring that certain parents be married or in a marriage-like relationship, expanding the number of potential parents could exacerbate problems upon dissolution even more.

Despite the potential drawbacks of recognizing multi-parent families, the best interests of the child will dictate their recognition in situations where failing to do so would deprive the child of an important psychological relationship and thereby cause substantial harm. The California framework provides courts with the power to make an appropriate assessment of parental recognition after a child’s birth by examining the nature of the relationships that the child has formed. In contrast, the British Columbia regime places this power in the hands of the prospective parents via contract without any assessment of the best interests of the child who is yet to exist.

A Narrative Approach

Many scholars have criticized the pervasive reliance on principlism in bioethical discourse, which often involves weighing demands for autonomy against choices that promote beneficence, because of its rigid, rule-based approach. Charon (2006) argues that principlism is inadequate for addressing the value conflicts that actually occur because “meaning in human life emerges not from rules given but from lived, thick experience” (p. 208–209). Hunter (1996) similarly notes that principlism “is an attempt to know generally and abstractly what cannot be known except through the particular case” (p. 316).

As an alternative to principlism, Brody (2002) suggests that we can only understand certain situations as segments of continuing narratives. Instead of applying principles like autonomy or beneficence at a level of abstraction that ignores the characteristics that are unique to each situation, a narrative approach requires identifying “who the parties are, how they understand themselves and each other, what terms of relationship have brought them to [a] morally problematic point, and perhaps what social or institutional frames shape or circumscribe their options” (Walker 1993: 35). When using this narrative framework, rather than assessing the rightness or wrongness of actions by appealing to universal principles, we justify or reject actions based on the extent to which they fit with individual life stories (McCarthy 2003).

Narrative ethics bears many similarities to casuistry though the two should not be confused. Narrative ethics suggests that we can glean moral insight and direction from the stories that people tell about their lives and specific situations that they experience. Casuistry involves a decision-making process in which one understands how to apply general principles by determining how they should be interpreted in various case studies. Thus, they both share an approach that emphasizes the importance of the unique characteristics of particular cases instead of the application of principles that are divorced from the specific circumstances and contexts. However, unlike the advocate of the narrative approach, the casuist seeks to identify paradigm cases in order to derive an interpretation of a general rule or to distinguish between multiple acceptable interpretations. In contrast, narratives provide a greater sense of ambiguity and complexity that undermine the application of a principle rather than clarify it (Miller 1994).

Statutory law, such as British Columbia's *Family Law Act* and California's amendment to the *Family Code* to include a "third parent law," tend to be inherently at odds with a narrative approach since legislation usually stipulates universal requirements that apply to all. Statutory law can be vague or ambiguous. Additionally, legislatures often enact statutes that may not contemplate future situations in which the law will be operative. In these cases, judges interpret legal provisions, and their decisions create common law that directs other courts on how to apply the statutes to particular instances. In fact, the common law system is cited as an example of casuistry since it relies on case studies to understand the application of rules and principles (Furrow et al. 2013). In circumstances where even the common law led to intuitively unfair results, kings, chancellors, and eventually courts could grant equitable relief based on the narratives and pleas of those who argued that the rigid application of the law to their situations produced unjust results.

One interesting characteristic of California's approach to multi-parent family determinations is that the *Family Code* amendment is not as rigid as statutory provisions often are since it provides judges with significant latitude to determine what is appropriate in each case. The amendment's language is permissive (i.e., "a court may find that more than two persons with a claim to parentage…are parents") rather than mandatory. The law also allows for the discretion on the part of a judge in determining whether more parents should be legally recognized. By framing the multi-parent provision in this manner, the legislature permits the presiding judge to take the narratives of the parties involved into account and reach a decision that reflects the context of the lives involved in the dispute before the court.

British Columbia's *Family Law Act* eschews the role of narrative by imposing a contractualist framework. What matters is who signs a written agreement and whether someone fits into a permitted parental category rather than the content of the story that the person communicates regarding how her life and personal meaning are intertwined with the other parties involved. British Columbia's approach represents a trade-off in which its legislature have opted for the certainty and security that one's status as a contractual party affords over judicial discretion to decide what is appropriate. By handling this trade-off in the opposite manner, California may facilitate a narrative approach but at the cost of leaving those who want to be considered parents at the mercy of a court's uncertain decision.

Perhaps the greatest revelation that comes from employing a narrative lens to evaluate the alternative multi-parent family frameworks that California and British Columbia espouse is that a key party's narrative is missing in the latter regime. California courts consider whether a multi-parent familial unit is appropriate having regard to narratives in which the child, who is a legally defined and existing person, is situated. In stark contrast, any narrative regarding what is in the best interests of the child at the moment when the prospective parents sign a British Columbia parentage agreement is incomplete because the personhood of the child is not yet established. The most important character in the narratives of the various parties is missing.

Conclusion

With the era of the nuclear family's dominance in our rearview mirror, our parentage laws must advance in order to reflect the constitutional reality of the fundamental right to same-sex marriage and reproductive technological innovations that permit multi-parties to qualify as legal parents. In addition, legislators and courts must recognize situations in which multi-parent families are in the best interests of a child.

California and British Columbia have provided two different conceptions of how we should recognize multi-parent families. California's *Family Code* defines who may qualify as a parent but allows courts to recognize more than two parents when it is in the child's best interests. The British Columbia *Family Law Act* provides prospective parents with the autonomy to decide who should be a legal parent without obtaining any endorsement from the courts. Though both frameworks reflect that the two-parent construct will not always mesh with modern society's de facto multi-parent realities, a family law system that places children at the center of moral concern should favor a California-style legal regime that evaluates their existing relationships with parental figures, considers the narratives of the key parties involved, and aims to limit situations that can potentially undermine their well-being.

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Part IV
Reproductive Perspectives, Practices, and Education

Reconceiving the Human Fetus in Reproductive Bioethics: Perspectives from Cultural Anthropology and Bioarchaeology

Sallie Han, Tracy K. Betsinger, Michaelyn Harle, and Amy B. Scott

Introduction

While individuals experience reproduction as a private, personal, and intimate matter, it is also always a public, social, and cultural concern. As such, not only is there a diversity of individual experiences but also of expectations across communities and histories. These are the starting points for an anthropological approach to reproduction and, especially, to the ethical questions and moral quandaries that the bearing, birthing, and raising of human children inevitably pose. The aim of this chapter is to suggest the contribution that anthropology might make to an emerging bioethics of reproduction that reflects, respects, and responds to what medical anthropologist Arthur Kleinman called "the local moral processes of everyday social life" (1999:78). Kleinman, among others, has discussed particularly the insights that bioethics might gain from cultural anthropology and, especially, ethnography (cf. Marshall 1992; Muller 1994; Turner 1998; Nelson 2000). Additionally, in this chapter, we argue for the relevance and necessity of a consideration of the practices and ideas of the past that bioarchaeology provides.

Our focus here is on the human fetus and the ascription of personhood. The moral status of the fetus is a central question of reproductive bioethics, haunting the real-life medical care decision-making of ordinary women and men, families,

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physicians, and other healthcare practitioners in addition to the reasoning of policy- and lawmakers. In the USA today, abortion on demand is a protected right that is typically framed as a woman's right to choose and a private medical decision that is reached between a woman and her doctor. At the same time, there are also organized movements to curtail the availability and accessibility of abortion services and care; these are based around the assertion that the fetus has a right to life because it, too, is a person. Notwithstanding the efforts of some states to introduce legislation defining personhood at conception, a "person" is understood in US constitutional law as a *born* person[1] (Robertson 2015), and in both law and medicine, the concept of viability—the ability of a fetus to survive outside the uterus—is used and applied. Yet, personhood is far from a settled matter in US society, where the institutions of law and medicine provide answers far more restricted and narrower than what the question of personhood asks: Who or what is a *person*?

The question is broad and deep and so are the consequences of how it is answered. The "person" is a foundational identity on which all other identities—such as gender, sexuality, race, ethnicity, and class—become imbricated. Anthropologists can tell us that the answer is not the same, nor has it been, for all societies and cultures. The ethnographic literature points to both the cross-cultural variation in understandings of who or what is a person and the common feature that the status of a person is not a natural fact to be taken for granted, but a cultural artifact that is the result of social effort. Significantly, personhood is constructed, established, conferred, and enacted through the performance of rituals. Ethnographers have described the rites of passage that involve a community in the recognition of its newest members. Judy DeLoache and Alma Gottlieb's 2001 edited book, *A World of Babies*, presents detailed descriptions of the rituals and symbols surrounding newborn infants and young children in seven societies. These rites do not necessarily occur at birth, much less before it. In fact, they might be observed in the days, weeks, and even years afterward, and their effects can be seen as accruing or accumulating over time. They include practices related to feeding, bathing, and naming children, and folklore and ceremonies pertaining to the first tooth and the first haircut. These activities not only display and deliver care for children, but they also meaningfully signal the status and identity of a nascent person. In other cases, bioarchaeologists remind us that it is the apparent inclusion (or exclusion) of individuals in mortuary rituals and funerary rites from which we can infer their status.

By now, bioethics in the USA has been critiqued thoroughly on the grounds of what Kleinman (1999) succinctly describes as the three "isms" of ethnocentrism, medicocentrism, and psychocentrism. The first refers to the problems of assuming and applying Western (European) concepts and values as universally valid ones, especially in the context of plural societies, prioritizing the frameworks and understandings of medical professionals over those of patients and families, and the casting of moral concerns as individual psychological issues rather than as social embodied experiences. The call for incorporating into bioethics the study of

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[1] Legal scholar John A. Robertson (2015) writes: "In Roe v. Wade all nine justices agreed that the use of "person" in the Constitution always assumed a born person, and therefore that the 14th Amendment's mention of person did not confer constitutional rights until after a live birth.

humanity, with its foundations in comparative cross-cultural perspective and emphasis on holism, has been issued across the disciplines (cf. Hedgecoe 2004; Farrell et al. 2014). However, Leigh Turner (2009) has taken anthropology and sociology to task for their own limited and even reductionist readings of bioethics: "We are certainly well past the time when it was possible to simply nod in agreement at the claim that bioethics engaged in normative work whereas the social sciences provide 'descriptive analysis'" (96). Anthropologists are not merely "descriptivists" nor are bioethicists merely "prescriptivists." In addition, the call to bring in anthropology has been more or less limited to cultural anthropology (specifically, medical anthropology) and ethnography. In this chapter, we suggest the particular contributions that bioarchaeology can make to a discussion of reproductive bioethics and the question of personhood.

Building upon our own and other previous research and scholarship in the anthropology of the fetus (Han et al. 2017), we bring into a conversation about reproductive bioethics the approaches and perspectives of anthropology. We are interested in the particularities of social and cultural ideas and practices and grounded in comparative cross-cultural and historical (and prehistorical) study and field-based research. In the discussion that now follows, we consider personhood as a status that is ascribed and negotiated, subject to change and contestation, and cross-culturally and historically variable.

Cultural Anthropology: Persons and Pregnancy

Being and becoming a person are processes requiring active human effort and imagination. This is a critical insight of the anthropology of reproduction and drawn from the immersive, longitudinal, community-centered, participatory method of ethnography that defines the field of cultural anthropology. Over the course of the discipline's history, cultural anthropologists have undertaken ethnographic research in the societies that they define as "abroad" and "at home" in support of the twin projects of making the strange familiar—and the familiar strange. In this section, we briefly consider pregnancy as an experience that is at once biological, social, and cultural. The focus is on what Han (2013) describes as the practices of "ordinary" pregnancy in the US that importantly and meaningfully accomplish the social and cultural work of person-making. These include practices of language, visual culture, and material culture.

It has long been asserted that language, and especially speech, distinguishes humans from all other living creatures. Not only has this been assumed in the myths and legends that various societies have told, but it is also built into the discipline of anthropology, which in the USA is organized into the four fields: archaeology, biological (or physical) anthropology, cultural anthropology, and linguistic anthropology. There is an understanding in the USA that certain exceptional animals can be engaged in conversation—in particular, household pets, especially dogs—but otherwise, the assumption is that other animals can communicate, but only people talk. In other cultures and societies, the concern is not necessarily that infants and small children are like little animals (e.g., suckling and crawling) but that they are recently (re)embodied spirits or souls. As such, they are vulnerable to being taken or tempted away. In her thickly descriptive account of infant care among the Beng, an ethnic group in Ivory Coast, Alma Gottlieb (2004) tells us that what motivates Beng parenting is the responsibility and wish of convincing newborns to remain in this life and not return to the afterlife. They are liminal beings in the classic anthropological sense of being betwixt and between two worlds. The number of rituals of infancy and early childhood (and eventually, initiation into adulthood) not only recognizes milestones in development and growth, but culturally speaking, they mark the strengthening of ties to this life. The babble of infants and young children is interpreted as a version of the tongue spoken in the other world, which they gradually forget as they embrace the customs of this one. Ethnographic cases such as this one serve as needed reminders about the range of human possibilities in terms of what we see people do and hear what they say about it.

In the contemporary USA, it is not uncommon for pregnant women, their partners, and other family and friends to engage in “belly talk” with an expected child in utero. Indeed, a number of pregnancy and parenting experts now prescribe what they call prenatal stimulation for the child. It is also promoted as good parenting in the context of popular anxiety and public concern with the “word gap”—that is, the difference in the number of words spoken to young children in poor versus privileged households and the inequalities in the measures of academic achievement that have come to be associated with it. However, in ethnographic interviews, pregnant women themselves described the significant attachments and bonds that they felt and believed their talk to be establishing with the children they actively imagined. In Han 2013, one woman, then 19 weeks pregnant, described her belly talk as a deeply meaningful experience: “I think maybe that’s when I imagine it as a baby—a future baby. Because I can translate from whatever that experience is to talking to an actual baby” (59). Poignantly illustrated here is that US women talk to their bellies not because they already assume the status of their babies as person but because doing so enables them to enact an anticipated relationship that in turn enlivens a pregnancy as “an actual baby.” Belly talk presents a linguistic teleology: only persons participate in language, and participation in language makes a person.

The same might be said for visual culture and being seen. Sight and vision are taken for granted as natural senses that merely grant access to an already known material reality. Yet, as cultural anthropologists and social historians have documented, sensorial perceptions are significantly *trained* (Geurts 2002). Historian Constance Classen (1993) gave the example of the changing value of the rose. The flower had been bred and celebrated for its perfume in early modern Western Europe but became cultivated and prized for its visual beauty during and after the Enlightenment, indicating a shift in the privileging of the olfactory to the ocular. Additionally, the social history of the rose illustrates that the human senses do not simply enable the apprehension of what exists already; they act upon the world, creating and constituting it anew. Researchers and scholars of reproduction are most familiar with fetal ultrasound imaging as an example of seeing as not only believing but bringing into being. Although its actual medical necessity has been called into question, the sonogram is both a routine practice of prenatal care in the USA and a ritual occasion for "seeing the baby." The expected child is no longer only imagined, its body is imaged and in so doing, it acquires corporeality. The sensations experienced in women's own bodies, including the first flutterings of fetal movements, were symptoms of the condition of pregnancy, but not necessarily reliable signs of a living, normal, healthy child. "It wasn't really real until we saw it" succinctly expresses a commonly held sentiment (Han 2013: 83).

Persons are not reducible to their bodies, according to the beliefs and practices of Christianity, Judaism, Islam, and other religions followed in the USA. Yet, there is also an assumption that there is no real, complete person without a body. The expected child's body becomes real and complete during the ultrasound scan as a sonographer narrates a tour of it and names its parts. Certain parts are attached with special importance and meaning for social and cultural as well as medical reasons—for example, the face, hands and feet, and heart. A child's head in profile and facial expressions is scrutinized for familial resemblances. However, most important for many expectant parents is the identification of its girl and boy parts. From an anthropological perspective, the images reveal information about the biological sex of an expected child—and, it is the social and cultural effort of kin, kith, and community that constructs its anticipated gender or social and cultural status as female or male.

In the USA, this is significantly accomplished with material culture and consumption. Clothing in particular both presupposes and constructs gender identity with its stereotyped color schemas of pink for girls and blue for boys. Shopping for—that is, on behalf of—an expected child and provisioning it with personal items like clothing accord it with the status of a person. At baby showers for expectant mothers, the giving and receiving of gifts for an expected child's enjoyment, like toys and books, involve the child in relationships not only with things but with people.

What these activities of ordinary pregnancy illuminate is that the question of personhood is not, in fact, an extraordinary one but a central concern around which social and cultural practices and ideas are organized. Reproductive bioethics are lived in everyday experiences.

Bioarchaeology: Personhood in the Past

Bioarchaeology, the investigation of human skeletal remains from archaeological contexts (Larsen 2015), is a biocultural specialty within the field of anthropology. Bioarchaeology is holistic in that it draws on biological (human remains), archaeological (the context in which the remains are recovered), and cultural (sociocultural information/context) components. As such, bioarchaeology, which has recently begun to examine issues of identity, has much to contribute to studies of identity and personhood in the past (Buikstra and Scott 2009). It can provide a unique degree of temporality and time depth, which may be lacking in contemporary studies of identity (Knudson and Stojanowski 2009). Granted, investigations of personhood and identity in the past are difficult, as individuals can have multiple identities at any one time, and those can change over the life course (Knudson and Stojanowski 2009). Additionally, evidence of identity is itself complex, as multiple factors may influence or affect that which is used to assess identity. However, with new methodologies and multiple lines of evidence, more insight can be gained through various analyses involving the study of the physical remains and their mortuary context, biogeochemical analyses, biodistance studies, and ancient DNA analyses (Knudson and Stojanowski 2009). By combining what is learned from human remains with historical/archaeological contexts and social theory, bioarchaeology contributes much to the discussion on identity in the past (Buikstra and Scott 2009).

One area that has not been expressly investigated is that of fetal personhood and/or identity. As previously stated, personhood is one of the first types of identity that is ascribed to an individual; however, limited research has been conducted to investigate whether a society regards fetuses as persons or whether that changes over time. Archaeology and bioarchaeology have begun to focus on children and childhood as a separate area of research (Lillehammer 1989; Kamp 2001), and there has been some increase in bioarchaeological studies of social identity in childhood (Tocheri et al. 2005; Halcrow and Tayles 2011), but these tend not to specifically address fetal identity and personhood. Overall, studies of fetal[2] and perinatal remains have received less attention, although this, too, is changing (Scott 2001; Lewis 2007; Lewis and Gowland 2007; Kinaston et al. 2009; Mays and Eyers 2011).

The lack of particular attention to fetal remains may in part be due to their absence from some communal cemeteries (Scott 1999, 2001; Lewis 2007; Saunders 2008), which may be explained by issues of preservation, excavation biases, misidentification, or lack of identification (Gordon and Buikstra 1971; Tocheri et al. 2005; Djurić et al. 2011). Moreover, their absence may be intentional, and the reasons for such selective burial practices are culture-specific. That is, issues of personhood, belief systems, infanticide, or other social policies may be influencing or determining whether fetal remains are buried in communal cemeteries (Gowing 1997; Sofaer Derevenski 1997a; Scott 1999; Orme 2001). The inclusion of fetuses in a cemetery, then, may be a function of the same factors, especially as it regards personhood (Scott and Betsinger 2017). It is not uncommon for different stages of childhood to be distinguished and identified in various cultural groups, including the recognition of the fetal period as separate from infancy or other stages (Scott 1999). In some situations, infants/fetuses were excluded from society and seen as "strangers" or "others" until recognition from the social group at certain ages or stages (Scott 1999, 2001). Ethnographic examples of incomplete personhood have outlined rites of passage that mark when a child becomes part of the community (e.g., DeLoache and Gottlieb 2000); these examples, of course, are far from

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[2] In bioarchaeology, fetuses are subsumed in the category of "perinate," which includes individuals aged between 28 weeks in utero and approximately 7 postnatal days. Bioarchaeologists are unable to determine whether perinatal remains represent a fetus who died in utero versus one which died shortly after birth, including preterm births. In this chapter, fetus and perinate are used interchangeably.

universal. In some cultures, infants are viewed as individuals with spirits and self-awareness or as spirits that must be cared for (Conklin 2001; Gottlieb 2004). In addition, other cultures would likely have viewed fetuses as simply human and full members of society despite their age (Scott and Betsinger 2017). In Christian societies, in which ensoulment is believed to be synonymous with conception, this may be especially true (Tocheri et al. 2005). The question, then, is whether fetuses in a particular society have personhood. To address this, mortuary context becomes paramount.

Study of mortuary context has been an integral part of archaeology for years, as human behavior is directly linked to mortuary treatment (Pearson 1999). The difficulty is, however, determining which aspects of mortuary treatment reflect the person being buried versus those doing the burial. It has been argued, however, that examining the treatment of the dead reflects, at least to some degree, the role of that individual in society (Rakita and Buikstra 2005). Aspects such as status, gender, age, and social role can influence mortuary treatment; however, since the mortuary context is the result of the actions of the living, the dead may be misrepresented (Pearson 1999). Mortuary practices may be "more reflective of the living than the dead and provide insight into their ideas and beliefs as it relates to the deceased" (Scott and Betsinger 2017:149). While Sofaer Derevenski (1997b) rightly argues that the burial of children is not just reflective of the parents' wishes, but also the social role of the children themselves, the mortuary treatment of fetuses/perinates is distinct, as their roles in life (if they lived at all) would be limited (Scott and Betsinger 2017). Perinatal burials may be more reflective of fetal identity and personhood, as their treatments would more directly reflect the views of the family and community. As Pearson (1999) points out, the mortuary treatment of fetuses reflects how adults view them, how they come to terms with their early deaths, and/or how they ascribe meaning to their deaths (103). By investigating mortuary treatment, then, we may be able to determine whether personhood was ascribed to fetuses/perinates.

The aim of this section is to present two case studies from differing historic contexts and geographic locations to investigate whether fetuses in those communities had personhood based on their mortuary treatment, thus, providing some historical comparison with contemporary beliefs regarding fetal personhood. To do this, the mortuary context of perinates is compared to that of "postneonates" (aged 7 postnatal days to 1 year) and "young children" (aged 1–4 years). Mortuary data, such as burial location, body orientation, body position, artifact associations, and/or coffin use is utilized for the comparison. If perinatal remains have burial treatment that is comparable to that of postneonates and young children, it may be concluded that they have comparable personhood.

Case Study: Postmedieval Poland

In the seventeenth to eighteenth century rural farming village of Drawsko, located in the west-central portion of Poland, community members were Catholic and followed typical Christian protocols in their mortuary treatment, including an east-west body orientation, minimal funerary objects, the use of burial shrouds, and interment in consecrated ground (Davies 1999; Pearson 1999; Scott and Betsinger 2017). Because of the Christian nature of the society, it was expected that perinates would be viewed as having personhood and that this would be reflected in their mortuary treatment. The details of this study are presented elsewhere (Scott and Betsinger 2017), but the results are summarized here. The results found that there was no statistical difference between perinates, postneonates, and young children for coffin use, burial goods, body orientation, and burial location (Scott and Betsinger 2017). These results indicate that perinates were viewed synonymously with postneonates and young children and that they did have personhood. One caveat to the results is that it could not be determined if the perinates represented live births or stillbirths; therefore, there is no way of knowing whether stillborn infants were treated differently, including being buried in other locations, as the unbaptized typically cannot be interred in consecrated ground (Murphy 2011). It is not clear, though, whether this would have impacted the belief that fetuses had personhood. As Murphy (2011) has documented, stillbirths and the unbaptized may have been buried in a distinct cemetery but still received standard Christian mortuary treatment, suggesting that they had a different or separate identity of being “unfit” for inclusion in communal cemeteries. This does not, however, suggest that their personhood status was viewed differently.

Case Study: Prehistoric Tennessee

In East Tennessee, the Dallas site (7HA1/8HA1) dates to the late Mississippian period/Dallas Phase (AD 1300–1400) and is characterized by maize-intensive agriculturalists. Dallas Phase towns comprise public structures associated with large platform earthen mounds, a central plaza, and domestic dwellings. These domestic dwellings are often marked by multiple building episodes suggesting continuity over generations by what has been interpreted as corporate kin groups (Sullivan 1986, 1995, 2001; Schroedl 1998). Within Dallas Phase communities, there is a strong gendered component to the location of graves and funerary object inclusion. Males are more likely buried within platform mounds and public buildings than females. Female burials on the other hand are typically associated with residences (Hatch 1974; Schroedl 1986; Sullivan 1986). Likewise, males are more likely associated with hunting and warfare activities (triangular projectile points, ceremonial blades, cores, and/or flakes, bone awls, and utilitarian celts), while females were more likely associated with shell, pottery, and other “culinary” and domestic implements (Hatch 1974; Sullivan 2001). Sullivan (2001) suggests the spatial dimensions of this mortuary patterning reflect "gender duality" rather than "gender hierarchy," reflecting differential access to alternate sources of power (i.e., females in the context of households and heads of kin groups and males within the public sphere).[3]

In comparing perinates with postneonates and young children, there were no statistical differences in body position or the inclusion of funerary objects. The most common type of funerary object inclusion consists of shell ornamentations (beads, pins, and gorgets[4]) and pottery for all subadult age categories. In fact, for perinates and postneonates, other types of grave goods are rare. It is noteworthy to mention that while shell ornaments and pottery still represent the most common type of funerary inclusion for older children, there appears a wider variety of funerary objects types with increased age.

Subadult burials occur in conjunction with adults in both the domestic sphere (within residences) and public spaces (platform mounds), although they are more likely to occur within domestic spaces. The exception of this patterning is perinates who are exclusively buried within the residential sphere. The lack of perinates may be a function of the small number of perinatal remains recovered from the site or deferential preservation. However, it may be suggestive of slight differences in the view of perinatal/fetal identity within the context of their association with mothers and the female matrilineal line. Their physical association with the maternal body may have led to their preferential burial in residential areas. The greater variation of funerary objects types and burial location in both the domestic and public sphere in older infants and young children may reflect that those children had a greater ability to obtain various types of social roles because they have lived for a longer period of time.

Overall, the results indicate that perinates were treated similarly to postneonates and young children and likely had comparable personhood. The exclusion of perinates from the burial mound, if not related to preservation or sample size, may indicate that even though they were viewed as persons, they maintained an identity distinct from older infants and young children. This may underscore how personhood is a negotiated and continual process, rather than a onetime ascription. As children age, their personhood becomes more firmly established, and additional identities related to gender, kin group, etc., are added. This may be reflected in the wider variety of funeral objects found with postneonates and young children. Another possibility is that perinatal remains were strongly associated with their mothers as, indeed, they were either in utero at the time of their death or died shortly after being born. This association may have meant that perinates were to be buried where mothers (whether their mothers had died or not) and women in general were interred: in the residences.

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[3] Additionally, Mississippian period communities have been interpreted as matrilineal societies based on ethnographic analogies of modern Southeastern tribes (cf. Knight 1990).

[4] A gorget is a polished circular shell pendant frequently engraved with similar recurring sets of themes, motifs, and iconography.

As with the Polish example, whether the perinatal burials represent stillbirths or live births remains undetermined. As a result, it is possible that the perinates at Dallas include both stillbirths and live births or only one category (presumably live births over stillbirths). Further research is needed to determine whether there may have been some variation in beliefs of personhood based on surviving birth.

Conclusion

The examples discussed here, drawn from ethnographic field research and from bioarchaeological studies, collectively illustrate how anthropology can contribute to the field of reproductive bioethics. These studies demonstrate that fetal personhood, which is a fundamental issue in reproductive bioethics, is something that is negotiated and ascribed and is an ongoing process. Ascription of personhood to fetuses is not a given and is time- and culture-specific. Cultural anthropology has an important role to play in providing insight to issues in reproductive bioethics, which has been noted by several scholars (Marshall 1992; Muller 1994; Turner 1998; Kleinman 1999; Nelson 2000; Hedgecoe 2004). Ethnography, in particular, offers broad cross-cultural comparisons that are essential for medical professionals as well as law and policy makers who interact with and represent an increasingly multicultural population. Bioarchaeology has only recently begun to explore issues of identity in the past (Knudson and Stojanowski 2009), and minimal attention has been paid to issues of personhood to date. Despite this, bioarchaeology can contribute to these issues as illustrated here, as the human skeletal record and the mortuary treatment of human remains may reflect, at least in part, the social identity of the individuals, including their ontology. Bioarchaeology can provide historical and prehistorical context and comparison that may not have previously been considered and is also a source of cross-cultural examples. Together, cultural anthropology and bioarchaeology are situated to make significant contributions to reproductive bioethics, as the research and studies discussed here demonstrate.

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The Ethics of Evangelism: Why You Can't Be a Good Physician and Support Crisis Pregnancy Centers

Corinne McLeod

Introduction

Most people in America have seen signs or billboards along the road reading a version of "Pregnant? Scared? Need help?" They are usually otherwise nondescript, featuring a phone number or website URL and sometimes a picture of a pregnant woman. Most people passing by pay little attention to them, unless of course they've found themselves unexpectedly expecting. Those who do notice might assume that the organizations that fund such signs are unbiased charitable groups seeking only to perform good deeds. Unfortunately, this is rarely the case. Such organizations, known as crisis pregnancy centers (CPCs) or pregnancy resource centers (PRCs), use strategies like the above billboards and advertisements for free pregnancy or sexually transmitted infection (STI) testing to attract primarily people of low socioeconomic status (SES) to their offices primarily for the purpose of dissuading those seeking an abortion. The methods used by these organizations violate the principles of medical ethics with such consistency that it is impossible for the healthcare profession to endorse this practice. The following will illustrate exactly what makes CPCs unethical from a bioethics perspective and how we should endeavor to withdraw from them any support from the mainstream medical community.

What Exactly Is a Crisis Pregnancy Center?

To an unsuspecting visitor, it is often difficult to distinguish a CPC from a regular clinic. They are often housed in quiet strip malls or office complexes with names like "Life Choices" or "A Woman's Choice." Most staff members wear scrubs or

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white lab coats and often carry stethoscopes as they escort clients back to consultation rooms, perhaps passing by an ultrasound machine or a room marked "laboratory." Seeing this veneer of apparent legitimacy makes it difficult for prospective patients to realize that these organizations are largely run by volunteers with no medical training and are in no way providing unbiased healthcare. A special investigative report prepared for US Representative Waxman in 2006 defines CPCs as "virtually always pro-life organizations whose goal is to persuade teenagers and women with unplanned pregnancies to choose motherhood or adoption." The goal of dissuading the "abortion-minded," as potential clients[1] are often termed in CPC documents, is the only objective behind the CPC movement and is pursued relentlessly, regardless of facts or patient health.

The first CPC is credited to Robert Pearson, established in 1967 in Hawaii. Experiencing great success, Pearson went on to create the Pearson Foundation to support other CPCs as well as write a handbook titled *How to Start and Operate Your Own Pro-Life Outreach Crisis Pregnancy Center* in 1984 (Stacey). Within the manuscript, Pearson provides advice for prospective CPC volunteers such as avoiding contraception counseling, using neutral advertising in the Yellow Pages alongside abortion clinics, and avoiding answering questions about whether they are a pro-life group (Stacey). The manuscript also recommends adopting "dual names": one name for attracting "abortion-bound women" to their organizations and another name to attract donations from the pro-life contingency (Stacey). Pearson instructs within that the "name of the game is to get the woman to come in as do the abortion chambers. Be put off by nothing... Let nothing stop you. The stakes are life or death" (Stacey). Although this manual was written more than 20 years ago, very little has changed with regard to CPC tactics. Most centers use names involving the word "choice" and neutral language on their websites to disguise the nature of their business, although many will have websites that attract like-minded donors separate from those targeting patients. They continue to try to advertise alongside abortion clinics, using key search words like "abortion" and "morning after pill," to confuse potential clients into thinking that they provide abortion services (Entsminger). But most importantly, they continue to relentlessly pursue their primary goal: stop abortions at any cost.

Facts are unimportant in the face of the dogma of preventing abortion; CPCs use discredited science and sometimes outright untruths to dissuade women from seeking abortion care. During counseling sessions by nonmedical volunteers, CPCs use the oft-touted and thoroughly disproven link between abortion and breast cancer as well as abortion and infertility and/or premature birth in addition to frighten women away from clinics (Stacey; Bryant et al. 2014). Statistics about the risks of the actual surgical procedure are heavily exaggerated. The link between abortions and mental health disturbances, or the "postabortion syndrome," invented whole cloth by the pro-life movement and discredited by the American Psychological Association, is

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[1] The use of the word "client" rather than "patient" is deliberate, as CPC counselors have no health profession credentialing and thus have no claim to the word "patient" in describing those who use their services.

often cited (Bryant and Levi 2012; APA Task Force 2008). One CPC in Texas was documented adding even further risks to the procedure by linking a previous abortion to IgA nephropathy and dialysis, stating that the abortion "messed up" the hypothalamus, leading to a "hormonal imbalance" in a woman's body, causing kidney failure (Patel 2015). Many go further trying to dissuade women from using any birth control at all by distributing pamphlets that suggest barrier methods provide no protection from sexually transmitted infections and/or pregnancy as well as links between hormonal birth controls and varying gynecological cancers (NAF 2006).

These kinds of "facts" are presented after a pregnancy test is administered free of charge, which is of course the primary attraction for most CPC clients. Some CPCs have been known to knowingly report false negative pregnancy results to their clients to delay women who would potentially seek an abortion (NAF 2006). For those centers that offer ultrasound services, ultrasounds are often not performed by licensed ultrasound technicians (NARAL Pro-Choice Texas 2014). Results are often fabricated, involving telling clients that they are further along in their pregnancy than they are to discourage the possibility of an abortion, showing clients negative or inconclusive ultrasounds and reporting them as positive, and in several notorious cases, showing clients their intrauterine devices and encouraging them to look at "their baby" on the ultrasound screen (Kutner 2015a).

Because these organizations are most often religiously motivated, they often aim to convert clients to evangelical Christianity over the course of their counseling sessions. CPC staff members will often offer free Bibles or prayers during sessions, as well as mention religious penalties for contraception or abortion use. Many CPCs that claim to provide prenatal support for mothers continuing their pregnancies do so in the form of a reward system, which gives mothers points for every Bible study or prayer group attended at the CPC that can be redeemed for formula, baby clothing, etc. (NAF 2006). Some keep a running tally of converted visitors to their establishment and use these numbers to attract religious donors (Life Choices 2015). The religious nature of these centers is concealed from clients until their appointments in order to ensure a captive audience. As one Texas-based CPC states on their website, they use the promise of free pregnancy and STI testing to bring in clients, as "we cannot offer alternative lifestyles and present the Gospel to our lost generation, if we don't have something they want" (Life Choices 2015).

However, the desire to provide healthcare or objective information is not prioritized at CPCs. The ideological goal of preventing abortion is paramount. If these organizations were completely separate from medical care or government funding, this would not be an ethical issue; after all, private organizations are entitled to their own beliefs. Unfortunately, this is not the case; CPCs often receive state and federal funding, creating a church-and-state separation issue apart from medicine (Kutner 2015b). Even more pressing than this are the ethical concerns surrounding the purposeful deception of clients with regard to the nature of CPCs and their lack of trained healthcare providers, as well as the harm that can be done to patients as a result.

The Ethical Problems with Pregnancy Centers

As with many topics in medical ethics, a discussion around ethics and CPCs can be brought back to four core principles: beneficence, nonmaleficence, justice, and autonomy (Beauchamp and Childress 2013). Although there are other ethical frameworks to use to analyze CPCs, these simple principles are used by medical practitioners with some frequency and are highly accessible to those on the front lines of clinical practice. However, as mentioned previously, most centers do not employ medical professionals, which could arguably negate their duty to the four principles of biomedical ethics. Given their assumption of the trappings of medicine and use of that power, however, it seems reasonable that CPCs should be expected to follow the ethical principles of standard medical practice. In other words, if they are to act like healthcare practitioners, they need to abide by the rules of healthcare practitioners. Thus, the following analysis assumes that CPCs would be ethically obliged to the ethical principles of medicine.

Even if they dispensed with the imitation of medical providers and simply considered themselves as doing faith-based counseling, this would not absolve trained healthcare providers from the sins of CPCs. For one, any healthcare practitioners personally involved in CPCs should distance themselves immediately, as should become clear from the ethical analysis to follow given that CPCs in no way abide by a standard of ethical practice that healthcare providers should adhere to. Additionally, many CPC clients have been or will be our patients as they seek medical care related to pregnancy. Educating them about their pregnancy options and the scientific evidence behind abortion and pregnancy care is the ethical duty of medical providers, including dispelling previous myths and reestablishing trust in the medical relationship.

Autonomy

CPCs violate the principle of autonomy in many ways, in particular regarding the concept of informed consent. There is a clear consensus in the medical and bioethics literature that providing complete and accurate information at the education level of patients is necessary to preserve patient autonomy in medical decision-making. This is now the standard of care in medicine, and patients expect their providers to facilitate autonomous decision-making through appropriate information disclosure. When CPC clients visit centers that have taken on the trappings of medical professionals, which is the common practice as described above, the same expectations of information disclosure are carried forward. As such, it easily follows that deliberately misinforming CPC clients of the risks of abortion and birth control is a violation of autonomy. When centers are deliberately misleading clients in their search for information about pregnancy options, they are not allowing for autonomous decision-making. Similarly, providing false pregnancy or ultrasound results robs

CPC clients of their ability to make informed decisions. Information sharing is a key part of autonomy in medical ethics—conversely, withholding desired information or falsifying information is a violation of this principle. Just as a patient cannot properly give consent for a surgical procedure without an explanation of risks and benefits of the procedure, CPC clients cannot be considered autonomous decision-makers about their reproductive choices without accurate information.

Deceptive practices on the part of CPCs are also a form of information withholding. When CPCs use the trappings of a medical practice to imply that they are licensed medical providers rather than religious organizations, they are violating the principle of autonomy by preventing patients from understanding the potential religious and political biases of the organization. Medical professionals are supposed to withhold their personal morals as much as possible in counseling and treating patients; ideally, they provide information to patients and help guide them through a decision-making process that is in keeping with their own moral framework. Part of the trust that is placed in the medical community comes from the mutual understanding of this ideal. CPCs exploit this trust by strongly implying their status as medical providers to draw clients in and further their own goals of preventing abortion. If CPC clients are unaware of the strong moral agenda present within CPCs, which may or may not coincide with their personal beliefs, their autonomy is compromised by placing trust in an untrustworthy source. The misleading information clients receive is then given additional weight given the assumption that the information is being given by a trained professional. This can easily lead to CPC clients being pushed into making decisions that are not actually consistent with their core values.

Nonmaleficence

The illusion of accurate medical advice creates potential harms for CPC clients, arguably violating the principle of nonmaleficence. Patients are sometimes given falsely negative pregnancy results or incorrect dating, often to discourage seeking out actual medical care and potentially getting access to an abortion. Autonomy issues aside, this can create considerable problems for CPC clients, regardless of the path they choose for their pregnancy.

For those who do pursue an abortion, delays to care means more difficulty accessing a provider, as many providers are not trained in later term procedures like dilation and evacuation. Legal barriers also present themselves as gestational age bans become more common; 21 states have thus far banned abortions after 20 weeks, and the US House of Representatives recently passed a 20-week nationwide abortion ban (Rewire Staff 2017; Pain Capable Unborn Child Act). The increased difficulty in access to abortion is undoubtedly the goal of CPCs, although the success of their strategy is dubious as data suggest that legal bans on abortion decrease safety of abortion rather than decrease the incidence of the procedure (Ganatra et al. 2017). Legal and medical education barriers to abortion are against the principle of nonmaleficence for this reason. For those able to access a safe, legal abortion, the risk of complications like hemorrhage, infection, and uterine perforation increases with gestational age. Although pregnancy is associated with 8–9 times more mortality than abortion (Raymond and Grimes 2012), the goal of any medical provider is to do the safest procedure possible, again underscoring the principle of nonmaleficence in helping patients to secure early gestational age procedures as much as possible.

For patients who decide to continue their pregnancy, the result is delayed access to prenatal care. This can lead to suboptimal prenatal care at best, but at worst, the potential complications of pregnancy, like preeclampsia or diabetes, may go unrecognized or untreated for longer periods of time. This can have serious consequences for the patient and her fetus, including stroke, seizure, end-organ damage, and maternal or fetal death (Cunningham et al. 2014). Along those same lines, when a non-expert performs an ultrasound and provides inaccurate results, pathology like fetal abnormalities and ectopic pregnancies may go unrecognized. Again, these can have serious and potentially lethal consequences for the patient. Finally, with the growing population of reproductive-age patients with complex medical problems, nonmedical counselors can give inadvertently poor advice about the safety of pregnancy in the setting of major medical comorbidities. Some patients have high rates of morbidity and mortality during pregnancy, such as those with congenital heart disease who are at eightfold risk of serious complications and death compared to the average patient (Opotowsky et al. 2012). CPCs have been documented diminishing the risks to encourage clients to continue their pregnancy, as was the case at one center in Texas (Patel 2015), potentially jeopardizing people's lives.

Justice

It is also important to consider that most CPCs locate themselves in areas with vulnerable populations, typically people of color and/or low socioeconomic status, who would be seeking low-cost or free pregnancy care. A study of CPCs in North Carolina showed that CPC presence is twice as high in areas with below-average median household income and high Hispanic populations (NARAL 2017). Two of the major umbrella organizations for CPCs, CareNet and Heartbeat International, specifically mention their "urban initiatives," a phrase that is usually a proxy for people of color (NWLC 2012). That these people, who often cannot afford another child, are disproportionately targeted for misinformation is a violation of the principle of justice. Justice implies equality between groups of patients, regardless of SES or color. There is already a known racial and socioeconomic divide in pregnancy outcomes, with those of color and low SES having increased rates of preeclampsia, preterm delivery, and fetal demise (Zhang et al. 2012). This is a known justice issue in the obstetrics community with myriad contributing factors that is currently being addressed from multiple perspectives. One way to intervene may be to limit CPC interference in these at-risk communities. As previously described, CPC clients are put at risk for worsened maternal and fetal outcomes via delayed access to care and/or misinformation. Given the connection between low SES, non-white ethnicity, and poor health outcomes, CPC targeting of these specific populations is exacerbating a known justice issue.

There is also the issue of financial support of CPCs as a justice issue, many of which receive substantial state and federal grants under abstinence-only education bills and social support services. Given the religious nature of the vast majority of CPCs, as well as the financial inefficiency of their services (one estimate gives an approximate $24 per patient in material goods despite the investment of millions of dollars in CPC programming (Kutner 2015b)), there is certainly a question of the appropriateness of such funding both from a church/state separation issue and an equality argument. Funds that are distributed to CPCs are intended primarily for those of low socioeconomic means—that they are distributed to such inefficient organizations is also worth considering as a social justice issue. Furthermore, given that the primary goal of CPCs is to prevent abortion rather than assist parenting, it is unclear whether their clients are adequately referred to other social programs like Women, Infants, and Children (WIC) or Medicaid that could provide further much needed help. The distribution of scarce financial resources to pregnant people is a significant justice issue. There is little evidence that CPCs significantly help and good evidence that they harm pregnant people. The fact that CPCs receive taxpayer money when it could be distributed to more effective programs is an injustice.

Beneficence

Beneficence is the only principle of the four that could be debated depending on one's political and ethical leanings. A more pro-life leaning position might argue that beneficence requires maintaining the pregnancy to promote the development of the fetus because it has equal moral status to the pregnant woman. Thus, CPC employees may feel that their actions promote beneficence because they are preventing abortions and thus allowing the fetus to be born, which would ostensibly be in its best interest. This is predicated on the assumption that CPCs help to prevent abortions at all, which has yet to be adequately studied, although many CPCs tout the numbers of supposedly prevented abortions on promotional materials. The pro-choice argument is that the pregnant person is the relevant recipient of beneficence and thus her perspective on whether or not fetal status is to be considered is most important. This is the viewpoint supported by bioethical literature, which posits that in the previable period when the fetus is not developed enough to survive outside the womb, the pregnant person can choose to confer "patienthood" onto the fetus (Chervenak and Mccullough 1996). If the pregnant person declines to acknowledge the fetus in this fashion, then she is the only relevant recipient of beneficence. After viability is attained, the fetus could at least theoretically survive independently of the pregnant person, which necessitates the consideration of the fetal "patienthood." The importance of the "patienthood" argument is that if the fetus is not a patient in the previable period, when almost all abortions are performed (Jatlaoui et al. 2016), then the four basic bioethical principles do not apply to it. Thus, the consideration of beneficence is only for the pregnant person, and the pro-life argument described above is invalid. CPCs are not promoting beneficence by attempting to prevent abortions by any means necessary, and in fact, providing an abortion may be considered beneficial by the patient particularly for protection of physical and mental health.

There is significant disagreement about the moral status of the fetus in biomedical ethics. However, most can agree that multiple factors are needed to determine whether or not a particular practice should be considered ethical. Looking at the complete picture surrounding CPCs and considering the violations of nonmaleficence, autonomy, and justice as previously outlined, it is not difficult to conclude that the practices of CPCs are not ethical and should not be endorsed by mainstream medical providers.

Conclusion

Going through this analysis, it should be clear that the business practices of CPCs are unethical and should be unacceptable to any provider of evidence-based medical care. Medical professionals work in a profession that values autonomy, honesty, and integrity in building our relationships with our patients. Even if those who choose to work with CPCs have the best intentions toward their clients and are truly trying to help, giving manipulative and false information does not honor these principles. As we try to move away from paternalism in medicine, it is important to respect patient autonomy by giving patients the information they need to make their own decisions. This should not be a bipartisan issue; all healthcare providers should be able to agree to respect the autonomy of our patients. However, strongly pro-life organizations of physicians like the American Association of Pro-Life Obstetricians and Gynecologists (AAPLOG) continue to endorse the practices of CPCs, i.e., the deception of pregnant people to further a pro-life agenda (AAPLOG 2010). It is important to continue to try to educate our colleagues and patients about CPCs and why they cannot be a part of ethically practiced medicine.

This is, of course, separate from the legal issues that surround CPCs, which lie in a legal gray area in terms of commercial speech and medical licensing. Attempts to regulate the advertisement used by CPC as a “truth in advertising measure” have been relatively unsuccessful, although legislation passed in California recently requires that CPCs identify themselves clearly as not being licensed medical providers (Reproductive FACT Act 2015). Previous legislation in this area has been overturned in the court system, and it is unclear if the California bill will be upheld. CPCs have yet to be legislated or prosecuted from a medical licensing standpoint.

From a medical professional standpoint, it is clear that CPCs are not ethical and should not be recommended to patients. Medical professionals must do their best to advocate for their patients by informing them as well as their colleagues about the nature of CPCs. Advocacy in legal arenas against state and federal funds going toward CPCs should also be undertaken, particularly in southern states, which have large numbers of CPCs and few family planning or abortion clinics. Allowing CPCs to go unchecked undermines the profession by eroding patient autonomy and sowing mistrust among our patient population. Not only that, the trust in the medical community's fiduciary relationship is undermined. As a profession that is constantly reexamining issues like informed consent, as well as combating the specter of paternalism in recent history, we cannot afford to have such a stumbling block to patient care.

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Doulas as Agents of Reproductive Justice Who Promote of Women's International Human Rights: An Evidence-Based Review and Comparative Case Study Between Brazil and the United States

Kathryn Mishkin and Luisa Fernandes

The Status of Global Women's Health

While monitoring bodies such as the United Nations are publicly committed to the promotion of women's rights to empowerment and health, the international human rights community is failing women in several areas. A human rights approach to health dictates that quality healthcare should be available to all women (Miller et al. 2016). However, quality healthcare is routinely not available to everyone. Sex discrimination kills women, be it through the preference of male babies leading to infanticide of girl children, through preference for boys to receive healthcare and vaccinations compared to girls, or through poor-quality health services for women (Bunch 1990). As girls become adults, institutional challenges including poverty, racism, sexism, and ageism impact quality of and access to maternal healthcare for women globally (Bakken et al. 2015; Hayes et al. 2011; Almeida et al. 2013). Institutional poverty and discrimination impacts maternal health through costly maternal healthcare, lack of transportation options to receive care, and women's lack of awareness of maternal healthcare options (WHO 2017). Furthermore, inadequate numbers of trained women's healthcare providers and the lack of provision of goods and services related to women's health lead to poor health outcomes among women (WHO 2015a). As of 2015, only 73% of births were attended by a skilled attendant worldwide, with varying rates of 96% in the Region of the Americas to 59% in the Southeast Asia region (Boerma et al. 2015). Performance on indicators for women's health is also logically impacted by the quality of care delivered. Analysis of Millennium Development Goal (MDG) Target 5.A, which focused on reducing the maternal mortality ratio (MMR) by three-quarters between 1990 and 2015, indicated that women's health is improving but that much work is yet to be

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done. While only 44% of countries achieved the MDG, during this time frame, the actual MMR was halved (Boerma et al. 2015). Still, the rate of preventable maternal deaths remains staggeringly high in low- and middle-income countries (WHO 2014).

The reliance on medical technology and interventions can ignore the reality of many women's lived experiences. As Miller et al. (2016) indicate, "in many facilities, over-medicalization of childbirth is common practice and can include excessive or inappropriate use of interventions" (Miller et al. 2016). For example, while the World Health Organization (WHO) recommends a Cesarean delivery rate that does not exceed 10 to 15 per 100 live births to optimize maternal and neonatal outcomes and while a 2016 Lancet Editorial indicated that nonmedically indicated Cesarean sections are unnecessary for maternal health, the global Cesarean section rate has been steadily increasing since 1990 (WHO 2015b; Betrán et al. 2016; Miller et al. 2016). An analysis of the Cesarean delivery trends in 150 countries from 1990 to 2014 shows that the global Cesarean section rate increased 12% since 1990 to a final rate of 19.1% (Betrán et al. 2016). However, great discrepancies among regions were observed indicating both gaps to accessing of medical care and the over-medicalization of health systems with unnecessary interventions (Betrán et al. 2016). For example, the Cesarean section rate in Latin America and the Caribbean in 2014 was 42%, 25% in Europe, 32% in North America, 19% in Asia, and 7% in Africa (Betrán et al. 2016).

In addition to the physical health outcomes for women, women's autonomy and empowerment also contribute to good health. While it is often assumed that maternal and child health are interlinked, women have unique and specific health requirements separate from children's health needs (Rosenfield and Maine 1985). The quality of physical maternal health outcomes is crucial, but the personal experience of the mother undergoing medical procedures during pregnancy, labor, and childbirth are is equally important to consider. Respectful care is a key component of healthy birthing facilities (Lalonde and Miller 2015). In spite of this, women are subjected to disrespect and abuse in the form of physical violence, non-consented clinical care, non-confidential care, non-dignified care, discrimination, abandonment, and detention in health facilities during the birthing process (Bowser 2010). Women of lower socioeconomic status, those having children out of marriage, and women infected with HIV feel especially discriminated against (Miller and Lalonde 2015). A commitment to reducing discriminatory practices against women effectively contribute to reducing other forms of oppression, be it through class, race, or other forms (Bunch 1990). This is especially true because discriminatory practices resulting in inadequate care produce poor maternal health outcomes (WHO 2015a).

Women also complain that they are not treated with the respect they expect during the maternal time period. Women report that they are not always asked for consent for medical procedures during delivery (Human Rights Watch 2011; Redshaw and Hockley 2010). Furthermore, even when women are asked to provide consent, some feel that information about risks and benefits for procedures is not always adequately explained (Human Rights Watch 2011). In general, the birth experience leaves many women feeling disempowered (Bohren et al. 2015).

The state of global maternal health is impacted by many intersecting factors that result in both poor physical maternal health outcomes and disempowerment because of poor care and discriminatory practices. Reproductive justice aims to overcome reproductive oppression with relation to reproductive health (including reproductive health services) and reproductive rights (legal rights to reproductive health) (Ross 2006). Equally, Forward Together, a social justice organization in the United States, set the definition as "the complete physical, mental, spiritual, political, economic, and social well-being of women and girls, and will be achieved when women and girls have the economic, social, and political power and resources to make healthy decisions about our bodies, sexuality, and reproduction for ourselves, our families, and our communities in all areas of our lives" (Asian Communities for Reproductive Justice 2005). This definition was later adopted by the United Nations Population Fund in 1994. In this way, reproductive justice can be used as a framework through which progress related to women's reproductive health and reproductive rights may be measured. The goals of reproductive justice may be realized through the provision of quality women's healthcare and through the promotion of women's control over their health.

Doulas are maternal healthcare professionals who engage in reproductive justice. Strauss et al. (2015) argue that doula care encourages reproductive justice because it results in better maternal and child health outcomes; improvements on the experience of pregnancy, childbirth, and the postpartum period by women; and lower medical costs (Strauss et al. 2015). John Kennell, the reputable pediatrician and researcher, is famously quoted saying "if a doula were a drug, it would be malpractice not to use it" (Maher et al. 2012).

Traditionally, doula is claimed as a Greek word, meaning "woman caregiver of another woman," "servant to the mother," and "mothering the mother" (DONA International 2017). Today, doulas are paraprofessionals who provide skilled care throughout a woman's childbearing years in the form of support during pregnancy, labor, and birth, as well as assistance during the transition to parenthood in the initial postpartum period (Kane Low et al. 2006). In this way, a doula can be compared to a community health worker who does not provide medical services but works alongside healthcare providers (DONA International 2017). The doulas' role is sometimes described as a bridge between mothers and medical providers, using their verbal and nonverbal communication skills to help fulfill the gap between the mother's desires and dreams and the reality of the medical care needed. Strategies and techniques used by doulas should accomplish the therapeutic goals to provide comfort, accelerate labor, aid fetal descent or position, and help mothers cope (Gruber et al. 2013).

We use a reproductive justice lens to understand the ways in which doula work supports women's health and the goals of the international human rights community through various human rights declarations and goals of the United Nations. We also provide a cross-cultural comparison of how doula work is promoted and challenged through national policies and programs in two case example countries representing different health systems, cultures, and stages of development: Brazil and the United States.

Doulas Improve Health Outcomes

Doulas support reproductive justice's goal of improving women's reproductive health. A 2008 study addressing evidence-based delivery, published in the *American Journal of Obstetrics and Gynecology*, concluded that a support person, including in the form of a doula, was among the most effective of the 41 birth practices reviewed—one of only three to receive an "A" grade (Berghella et al. 2008). Doulas support six evidence-based birth practices including allowing labor to begin on its own; walking, moving around, and changing positions throughout labor; bringing a loved one, friend, or doula for continuous support; avoiding interventions that are not medically necessary; avoiding giving birth on the back and following the body's urges to push; and keeping mother and baby together (Berghella et al. 2008).

Furthermore, doula care is associated with good health outcomes for mother and child. A systematic Cochrane review of 23 randomized controlled trial studies, from 16 countries, involving 15,288 women concluded that women who had used a doula during labor were 28% more likely to have a spontaneous vaginal birth compared to a Cesarean section delivery and that they were more likely to have a shorter labor time compared to women who did not use doulas (Hodnett et al. 2013). Randomized controlled trials have supported the finding that Cesarean section delivery occurs less frequently among doula-assisted births compared to women in a control group, not using a doula (McGrath and Kennell 2008; Kennell et al. 1991; Campbell et al. 2006). In the United States, findings from research following Medicaid-funded births suggest that doula care is associated with lower odds of preterm birth, controlling for maternal race-ethnicity, age, hypertension, and diabetes (Kozhimannil et al. 2013a, 2016). Apgar scores are higher for infants born to mothers who were supported by doulas (Hodnett et al. 2013; Sauls 2002), and mother-child bonding is reported to occur quicker with doula-assisted care (McGrath and Kennell 2008; Sosa et al. 1980).

Doulas Promote Women's Empowerment

Doulas improve women's experience during pregnancy, childbirth, and the postpartum period. Women who are assisted by doulas report more satisfaction with the birth process compared to women who are not, and this may be due to the fact that women feel that they have more control over the birth process when assisted by a doula (Sauls 2002). It has been argued that the birthing process can be disempowering to women, especially in a hospital setting (Cheyney 2008). Because the average woman is, understandably, less educated about medical procedures compared to her medical provider, she may feel that her opinion about her care is less valuable compared to that of her health provider (Cheyney 2008). Furthermore, some women report feeling that they were not provided with adequate information about the medical interventions that they are about to undergo by their medical providers (Cheyney 2008).

Knowledge is power, and this lack of knowledge regarding one's rights to health, an understanding of the health system, and familiarity with evidence-based practices can result in women feeling like they have less control over their care. Doulas strive to re-balance the knowledge gap between birthing women and providers by providing information about the birth process (Cheyney 2008). Research from Mexico found that women who used doulas described their birth experience in very different ways compared to women who did not use a doula (Campero et al. 1998). Women who used doulas expressed the "feeling of having some rights," when speaking to medical professionals about the quality of their care, while women who did not use doulas did not express these feelings (Campero et al. 1998).

Research indicates that doulas "ensure that informed consent is accomplished and that the woman's personal birth choices are respected" (Meyer et al. 2001). Informed consent serves as a form of information sharing, and this plays a significant role in the degree to which a woman feels empowered to make decisions about her healthcare. Because doulas promote informed consent, they facilitate women's control over the medical care that they receive. They promote equity because they assist women to make informed decisions about their health (Koblinsky et al. 2016).

In addition, doulas help clients navigate the maternity care health system and locating resources (Strauss et al. 2015). Doulas may assist women living in areas where medical care is scarce (Kozhimannil et al. 2016). Their provision of prenatal and postpartum care can reduce the burden of these women to travel to health centers and hospitals. Additionally, Strauss et al. (2015) argue that doulas can reduce health disparities by assisting women who are most vulnerable (Strauss et al. 2015). Doulas are by nature community-based health practitioners, and they may be more able to reach women through culturally appropriate means compared to traditional hospital professionals (Strauss et al. 2015).

Doulas Reduce Healthcare Cost

Doula care is linked to lower healthcare costs for a variety of reasons. Because doula services are associated with lower Cesarean sections, which are expensive, and because women who use doula services are less likely to suffer from medical complications, costs related to childbirth are lessened (Kozhimannil et al. 2013a). Furthermore, because epidural use and analgesia use are less common with doula-assisted births, expenses related to these medications are also reduced (Kozhimannil et al. 2013a, b, 2016).

In the United States, the Institute of Medicine estimates that each avoided Cesarean section saves $4459, and each avoided epidural saves $607 (Kozhimannil et al. 2013b; Kozhimannil and Hardeman 2016). Hayes et al. (2011) estimated that on average, doula-supported deliveries among Medicaid beneficiaries regionally would save $58.4 million and avert 3288 preterm births each year (Hayes et al. 2011). Of 10,000 simulated scenarios comparing Medicaid-funded deliveries with doula support to Medicaid-funded births, 73% resulted in cost savings, and 25% were cost-effective (Kozhimannil et al. 2013b; Kozhimannil and Hardeman 2016).

International Human Rights and Reproductive Justice

The goals of reproductive justice are admirable, but without support in the form of legislation, public backing, government collaboration, and routine evaluation, it can be both difficult to realize the goals and quantify success. In many ways, the goals of reproductive justice align with the objectives of international human rights. While human rights support people's autonomy over themselves and promote the idea of self-determination, certain human rights clauses and conventions specifically speak to women's access to healthcare service, women's control over healthcare, and health equity. The promotion of reproductive justice therefore serves as a key component of the goals of many human rights declarations. It is through these conventions that we can understand the power of doulas to promote human rights. Likewise, we argue that it is possible to assess the success of the goals of reproductive justice through some international human rights.

Because doulas may serve as agents of reproductive justice, their services may be used to complement and supplement activities targeting women's rights through the establishment of declarations and covenants for international human rights. This paper focuses on the ways in which doulas may support the promotion of international human rights through the Universal Declaration of Human Rights, the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW), and the Sustainable Development Goals (SDG).

Universal Declaration of Human Rights

The Universal Declaration of Human Rights was signed in 1948 and serves as the first signed declaration developed by the United Nations (UN). As the first signed document, equality and equity were key components throughout. Article 25 is especially in line with the aspirations of reproductive justice, and it states that "Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including [...] medical care and necessary social services, and the right to security in the event of unemployment, [...] or other lack of livelihood in circumstances beyond his control" (UN General Assembly 1948). Doulas promote the standard of living highlighted in this Declaration because they are focused on ensuring that pregnant women experience good quality physical and emotional health. Furthermore, this article also details "Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection." Because doula care is associated with better health outcomes in the form of shorter delivery time, lower odds of preterm delivery, better Apgar scores, and better mother-child bonding, doula care may serve as a kind of special care and assistance.

Within the Declaration, Article 2 states that "everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, color, sex, language, religion, political or other opinion, national or social origin, property, birth or other status." Doulas contribute to this article through providing health knowledge to all women in the hopes of improving the birth experience.

CEDAW

The Convention on the Elimination of All Forms of Discrimination Against Women, formally signed in 1979, defines discrimination against women and provides a framework for action to eliminate this discrimination by nations. Within CEDAW, Article 12 obligates that "parties shall take all appropriate measures to eliminate discrimination against women in the field of healthcare in order to ensure […] access to healthcare services, including those related to family planning," as well as "ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation" (UN General Assembly 1979). Doula services support evidence-based prenatal, birth, and postpartum practices and, as a result, reduce the risk of discrimination against all women.

Sustainable Development Goals

The Sustainable Development Goals of the United Nations were established in 2015 to enable progress with regard to all forms of development including with regard to women's health and rights. Goal 3: Good health and well-being aims to "reduce the global maternal mortality ratio to less than 70 per 100,000 live births by 2030" and to "end preventable deaths of newborns and children under 5 years of age, with all countries aiming to reduce neonatal mortality to at least as low as 12 per 1,000 live births and under-5 mortality to at least as low as 25 per 1,000 live births" (UN 2015). Because doula care reduces the odds of preterm birth and is associated with a lower rate of Cesarean sections as well as with better Apgar scores and maternal-child bonding, doula support should be considered as a strategy to help nations achieve Goal 3. Furthermore, Goal 5: Gender equality focuses on ensuring "universal access to sexual and reproductive health and reproductive rights." Doula support empowers women to make healthy decisions about their bodies during the pregnancy and labor and delivery.

A Practical Analysis of Doulas, Reproductive Justice, and International Human Rights

Doula care may be implemented and supported through various means. Depending on the cultural, political, and social context in a country, doula care can be valued differently, and this difference in principles can affect how successful doulas are at completing their work. We argue that these same differences can also play a role in how international human rights that support reproductive justice may be defended. We provide a cross-comparison of two distinct case examples of countries where doula care is provided, the United States and Brazil. This comparison provides a practical application of our hypothesis that countries adopting doula-friendly policies may better promote reproductive justice.

We chose to analyze Brazil and the United States for specific reasons. According to Elias and Cohn (2003), while American analysts typically choose to look at European systems for the comparison of public policies on health with the United States, Brazil may also be used for comparison because of its high relevance to the American context (Elias and Cohn 2003). Brazil is similar to the United States in terms of its diverse racial and ethnic makeup, its vast geographic differences, and its situation of social inequality (Elias and Cohn 2003). Brazil also faces similar challenges to the inclusion of certain people in public health policies, considering that, historically, a large portion of the population was excluded from public health coverage leading to the preference for participation in private health plans (Elias and Cohn 2003). Because the United States and Brazil experience similar social and public health challenges but incorporate doula care into public health policies and health provision practice differently, these countries serve as an excellent comparison for understanding how doulas facilitate reproductive justice, depending on context. Table 1 describes the comparison of healthcare system and doula services available in the two countries.

Recently, both countries have adopted legislation that strengthens the provision of maternal and child healthcare. In Brazil, the Stork Network was established in 2011 to improve communication between local health systems and the federal level to strengthen quality of care through the incorporation of best practices for maternal and child health, increase value-based payments, and decrease fee-for-service payments for Cesarean section deliveries (Sartori Fernandes and de Gouveia Vilela 2014). In the United States, the passing of the Affordable Care Act in 2015 created an unprecedented opportunity to discuss the maternal care model because of its goals to improve health outcomes, increase satisfaction with the care experience, and reduce costs align with evidence-based childbirth practices (Strauss et al. 2015).

Brazil employs a national universal public health system known as Unified Health System or “SUS” (Macinko and Harris 2015). Through the public health system, universal access and coverage is available at primary, secondary, tertiary, and surveillance levels (Macinko and Harris 2015). This system coexists with a private system that is primarily comprised of private insurance companies as well as direct payment care services. Currently, 86% of the population depends exclusively on SUS, and 24% use private health insurance (Fertonani et al. 2015), with the total expenses for healthcare of 8.3% of the GDP or $947 per person (World Bank 2017a). In Brazil, 80% of births are paid for by the government, with the average cost of delivery in a hospital being $160 for vaginal deliveries and $224 for Cesarean section deliveries (da Gama et al. 2016; Cavassini et al. 2012; Le et al. 2014).

In contrast, the United States employs a largely private system, comprised of different private health insurance companies, and two publicly funded programs: Medicare which covers people older than 65 years and people with disabilities and Medicaid which provides care for anyone under 133% of the poverty line and all pregnant women (Centers for Medicare and Medicaid Services 2013). After the Affordable Care Act (ACA) was enacted in 2015, millions of American gained health coverage, but as of September 2016, 12.3% of adults ages 18–64 years and 5% of children 0–17 years old remained uninsured (Martinez et al. 2017). The total healthcare expenditure with healthcare is considerably higher than Brazil, achieving 17.1% of GDP, which can be translated to $9403 per person (World Bank 2017a). In the United States, the government pays for about half of all births, with an average cost of $3500 per delivery (Childbirth Connection 2016; Agency for Healthcare Research and Quality 2017).

Doulas in Brazil

In Brazil, two different groups of doulas can be identified in the country: doulas who work as autonomous professionals in the private sector and the community doulas who volunteer at public birth homes and hospitals. Private doulas are paid out of pocket by women, and their services are costly. They provide support during pregnancy, labor, and after delivery. Community volunteer doulas are commonly members of the community who are served by the hospital themselves (Silva et al. 2016). They support women during labor after women are admitted to the hospital or birth home. The first registered community volunteer doula program was implemented at the Hospital Sofia Feldman in 1997. This program was later expanded to all the other public hospitals in the town of Belo Horizonte (de Castro Leão and Bastos 2001). In spite of the comprehensive training for community volunteer doulas, no standardized training for doula care exists in Brazil. Healthcare professionals and pregnant women themselves may not be aware of how to work with doulas, and a lack of structure in hospitals facilitating doula care can result in the devaluation of doula care (Silva et al. 2016).

In 2006, the Brazilian Ministry of Health and National Policy on Integrative and Complementary Practices included doulas as traditional medicine and alternative and complementary medicine professionals (Brasil Ministério da Saúde 2006). In 2013, doula work was recognized as a formal occupation, under the group "technologists and technicians in complementary and aesthetic therapies" (Brasil Ministério do Trabalho e Emprego 2013). This recognition granted doulas a professional status, allowing them to be included on payrolls and tax returns, and it guaranteed their rights as workers (Brazil 2017).

Doulas in the United States

In the United States, an estimated 6% of births are attended by a doula, and 27% of women who did not use a doula during birth say they would have liked to have had been assisted by a doula (Declercq et al. 2013). The majority of doulas who work in the United States are paid out of pocket. The exception is in two states, where Medicaid funding for doula care exists. In 2013, the Centers for Medicare and Medicaid Services (CMS), Center for Medicaid and CHIP Services (CMCS), and Provider Resources, Inc., recommended providing coverage for continuous doula support during labor among its recommendations (Kozhimannil et al.

Table 1 Comparison of healthcare, maternal health, and doula care systems in the United States and Brazil

	Brazil	United States
Healthcare system	Universal coverage, 100% have health insurance	87.7% Adults have health insurance
	Healthcare GDP, $947/person	Healthcare GDP, $9403/person
	Stork Network (2011) strengthens maternal care	Affordable Care Act (2015) strengthens maternal care
Doula services available	Private doula: paid out of pocket Public hospital volunteer doulas: since 1997	Private doula: paid out of pocket in all states except Oregon and Minnesota
	No standard training for private doulas but formal training for public hospital volunteer doulas	No standard training, but DONA training often used
	No national data about births attended by doulas	An estimated 6% of births are attended by a doula
Policies supporting doulas	Right to Companionship During Birth Act (2005) guarantees women's right to have a companion of her choice during labor	ACOG Committee Opinion (2014): "The continuous presence of supported personnel, such as a doula, is among the most effective tools to improve labor and delivery outcomes"
	Since 2014, 5 states and 17 cities legally grant women the right to companionship allowing doulas to enter public and private hospital as part of birth team, not substituting family members	
	National Policy on Integrative and Complementary Practices (2006) recognizes doulas as a member of a birth team Stork Network (2011) funds doula training using federal resources Doulas are incorporated in the Brazilian classification of occupations (2013)	Centers for Medicare and Medicaid Services (CMS), Center for Medicaid and CHIP services (CMCS) and Provider Resources, Inc., recommended providing coverage for continuous doula support during labor Oregon (2013) and Minnesota (2015) started covering doula service through Medicaid

2013a). Additionally, the CMS Preventive Services Rule (42 CFR §440.130(c)) in 2013 expanded the definition of professionals eligible for reimbursement of preventive services to include doulas (Minnesota State Senate 2013). In 2013, Minnesota introduced legislation to provide Medicaid funding for doula services including childbirth education and support services, including emotional and physical support provided during pregnancy, labor, birth, and postpartum (Oregon Health Authority 2015). Additionally, Oregon began reimbursing for doula services maternity case management services and labor and delivery services using Medicaid funding in 2015 (ACOG 2017). In the United States, several doula training options exist, but most are included in the umbrella of trainings offered by the Doulas of North America (DONA) International, a nonprofit organization that was founded in 1992 to professionalize the work of doulas (Berghella et al. 2008). Since its inception, DONA has certified doulas in all states of the United States (Berghella et al. 2008).

Comparison of Embodiment of International Human Rights

As previously discussed, doula care may be supported and even promoted through international human rights that promote women's right to health and empowerment. A comparison of the status of Brazil and the United States in relation to these women-specific international human rights declarations and covenants can help to illustrate the ways in which doula care may be facilitated. Brazil and the United States are both member states of the United Nations and as such have the power to promote efforts to guarantee women's reproductive justice through specific international human rights conventions and declarations. Furthermore, a comparison of scores on maternal and child health indicators provides concrete examples of the maternal health situation in both countries. The international community is focused on improving three maternal and child health indicators: the infant mortality rate (IMR), the maternal mortality rate (MMR), and the Cesarean section rate.

Both countries signed the Universal Declaration of Human Rights in 1948 (UN General Assembly 1948). Through signing, they publicly declared that they were committed to the statements included in the Declaration.

In 1979, both the United States and Brazil were present for the creation of CEDAW and signed the covenant as present member states. Protocol dictates that United Nations conventions be ratified by a country's legislative structure in order to become a policy guideline for the country. Brazil ratified CEDAW in 1984 (UN 2017), and this ratification occurred immediately after 20 years of military dictatorship. In spite of the fact that the United States sponsored CEDAW, to date, the United States has not yet ratified it (United Nations 2017). This has effectively limited the influence of the covenant on women's health policy in the United States (UN 2017; United Nations 2017).

In 1995 both countries were present at the Fourth World Congress on Women in Beijing, where women's rights were internationally recognized and a platform for engagement with women's empowerment was established (United Nations). After the 1995 conference, the platform for action has been periodically monitored at subsequent meetings, including the last one, Beijing +15 (United Nations). Both Brazil and the United States attended Beijing +15, and Brazil has diligently published follow-up reports related to women's empowerment and health, but the United States has not presented reports about their plan of action for women's equality, development, and peace (United Nations 2010). Finally, following the conclusion of the Millennium Development Goals, in 2015, both the United States and Brazil endorsed the Sustainable Development Goals. Brazil has joined the High-Level Group, alongside with eight other countries, to provide political leadership, guidance, and recommendations for the 17 Sustainable Development Goals (Swedish Government Initiative 2017).

Maternal and Child Health Indicators

The infant mortality rate (IMR), the maternal mortality rate (MMR), and the Cesarean section rate guide our understanding of how each country is implementing policies related to women's health and women's rights. In Brazil, the IMR decreased from 129 deaths/1000 live births in 1960 to 15 deaths/1000 live births in 2015 (World Bank 2017b). The United States had a lower baseline IMR in 1990 compared to Brazil, at 26 deaths per 1000 live births, and successfully decreased this rate to 6 deaths per 1000 live births in 2015 (World Bank 2017b).

In Brazil, the MMR was halved from 1990 to 2015, from 109 deaths/100,000 live births in 1990 to 44 deaths per 100,000 live births (World Bank 2017c; Dias et al. 2016). In spite of this, the maternal mortality Millennium Development Goal of reducing maternal mortality by 75% was not achieved. Again, the United States started with a lower baseline rate compared to Brazil, with 12 deaths/100,000 live births in 1990. However, compared to Brazil, the United States did not successfully reduce MMR in the same way as Brazil. While the United States started with a MMR of 12 deaths/100,000 live births in 1990, MMR increased slightly to 14 deaths/100,000 live births in 2015 (World Bank 2017c). In fact, of the high-income countries, the United States changed from having one of the lowest MMR in 1990 to having the highest in these 25 years (Shaw et al. 2016).

The Cesarean section rate in Brazil is high at 57% across the country in 2014 (Nakamura-Pereira et al. 2016). In the United States, an estimated 32% of women delivering deliver by Cesarean section, a significant increase from 4.5% in 1965 (CDC 2015; Gregory et al. 2012).

Implication for Practice and Policy

We argue that doulas are key stakeholders in women's reproductive rights and reproductive justice and systematically including doulas in health systems could facilitate the achievement of the goals of reproductive justice and international human rights. Our cross-cultural comparison between Brazil and the United States illustrates that there are several means to implement doula care.

While both the United States and Brazil have successfully lowered IMR, MMR continues to challenge both countries. While Brazil successfully significantly reduced MMR, MMR is still considered to be exceptionally high by international standards. The United States has a relatively low MMR compared to Brazil, but no progress has been made to reduce MMR since 1990, as indicated through documented MMR. Furthermore, while the United States has a lower Cesarean section rate compared to Brazil, both countries have higher rates than is recommended by the WHO (2015b).

While Brazil has actively participated in international human rights goals to promote women's rights, the United States has participated less actively. We believe that Brazil's faster adoption of women's human rights agreements compared to the United States could be one of the factors contributing to the progress the country has made in relation to MMR. Whereas the United States has been willing to develop human rights treaties and covenants for other countries to sign, it has been less willing to sign those same documents itself. It is our understanding that this commitment to engagement in international human rights has a direct impact on prioritization and direction to health policies that contributed to lowering the MMR. Furthermore, the difference in dedication to women's rights in particular may help to explain the significant improvements in both countries' IMR. Meanwhile, IMR has significantly decreased in the United States and Brazil. This suggests that both countries are focused on infant health, and the disparity in improvement between maternal and infant health in the United States reflects the fact that infant care may be more of a priority compared to maternal care in the United States (Rosenfield and Maine 1985).

We argue that perhaps this same disparity in dedication to women's rights may play a role in how doula care services are provided in each country. Whereas doula care is facilitated through the public health system in public hospitals in Brazil, doula care is less easily included in the formal healthcare infrastructure in the United States. We have argued that doulas improve women's lived birth experience, and by Brazil incorporating doula care into public healthcare, Brazil has visibly made improving women's experience of healthcare a priority through this facilitation of doula care services.

However, while Brazil shows a high commitment to international human rights, Brazil must commit to the United Nation call for action "Too much, too soon, too late, too little," to improve quality of maternal health (Miller et al. 2016). This call to action describes the two realities that occur within the field of maternal health impacting quality and safety. On one side, there are low-income countries that cannot offer sufficient care and intervention and timely to all women. On the other side, there is an excess of unnecessary maternal medical interventions conducted too soon, which results in additional complications and costly provision of services. This over-medicalization of childbirth can lead to services that are not medically necessary including Cesarean sections (Miller et al. 2016). By committing to this call to action, Brazil may address its excessive Cesarean section rate. Incorporating doula care services into all regions of the country may assist in this task, as doula care is associated with fewer Cesarean sections (Hodnett et al. 2013).

The United States must demonstrate higher commitment to reproductive justice and international women's rights. Through ratifying covenants such as CEDAW or providing routine reports about efforts undertaken to promote women's rights, the United States will remain accountable for its actions to the global community and will fight to improve the status of women. An expansion of coverage for doula care through Medicaid would improve women's birth experiences and improve overall health outcomes (Hodnett et al. 2013). Incorporating doula services into routine maternal care could also assist the United States in reducing its MMR, since doula care is associated with good maternal health (Berghella et al. 2008).

Both countries should adopt standardized trainings. In order to continue to promote doulas as agents to reduce health disparities, Strauss et al. (2015) recommend "training and hiring doulas who are trusted members of the communities most at risk for poor health outcomes, with attention to racial, ethnic, geographic, socioeconomic, cultural, and linguistic factors" and "ensuring that doulas are trained in cultural competency, trauma-based care, and support services that are available for low-income pregnant and postpartum women" (Lothian 2009; Strauss et al. 2015). An agreement of the minimum criteria for doulas training, incorporating each country and/or region cultural perspective, would not only be beneficial to women and doulas but also help to overcome one of the barriers for doulas being integrated in the birth team, the lack of understanding by other professionals of the doula's role.

We recommend that both countries invest in research to identify the impact of doulas on the public health system, especially considering quality of care and cost-benefit analysis. Little research about doulas exists in Brazil, and this does a significant disservice to both Brazil's public health system and stakeholders in global health. By understanding how doulas impact public health in Brazil, Brazil may develop strategies to facilitate their work, and other countries may look to Brazil for guidance related to promotion of doula care. Public health societies and private societies invested in health including physician society organizations would be able to use analysis about doula care to support the use of doulas. Furthermore, analysis of doula care should facilitate evidence-based practices during labor and childbirth.

Conclusion

Doulas are important stakeholders in international human rights promoting women's rights and women's empowerment. Their promotion of maternal health through improving health outcomes, promoting women's control over their health, and reducing cost-related health disparities embodies the goals of several United Nations goals and declarations including the Universal Declaration of Human Rights, the Convention on the Elimination of All Forms of Discrimination Against Women, and the Sustainable Development Goals. Incorporating doula services into health systems may serve as an important strategy to improve maternal health. While doula care is provided in both the United States and Brazil, services vary, and each country faces different challenges to its doula services due to the unique cultural and political norms. Both countries have areas for improvement, but they are committed to women's health and the goals of reproductive justice. We argue that strengthening doula care services should be promoted as a practical approach to realizing better maternal health.

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Reproductive Flourishing: A Framework for Teaching Reproductive Ethics in Clinical Education

Amy Michelle DeBaets

Introduction

Decisions about reproduction—whether, when, and how to parent children—are among the most important and impactful decisions that human beings make in our lives. Reproductive decisions affect virtually all of our other life choices, regarding education, careers, partners, and opportunities that are open or closed to us. When we make decisions about becoming parents, we make decisions that affect the shape of our whole lives and the lives of our children. Becoming a parent is not a decision that anyone should make lightly. Children are, by any measure, a major investment in time, money, and emotional and physical care.

And the decision about whether to become a parent is only the first of many major decisions that happens that profoundly affects both the parents and their child(ren). The timing of pregnancy and the choice to parent make a difference, in many cases, in the parents' access to resources such as education and jobs, even though discrimination against pregnant women is illegal. Pregnancy is physically demanding and can risk the pregnant woman's[1] life and health, especially in the United States, where maternal mortality is rising and remains the highest among all wealthy nations. Childcare is also expensive in the United States, and high-quality options remain out of reach for many. Healthcare can be difficult and costly to access, along with housing in areas with good schools.

But parenting can also be one of the most rewarding experiences one can have in life. Raising children is a tremendous opportunity to enjoy assisting young people

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[1] While this chapter will generally refer to parents in gender-neutral terms, "women" will occasionally be used to refer to people who are pregnant. This is intended to appropriately identify the gendered nature of pregnancy and is not intended to exclude transgender men who may also become pregnant and whose particular issues will be addressed in a case study.

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to grow, develop, and find their way in the world. Bringing up children can be an amazing joy and privilege unlike any other. Seeing the light in their eyes as they learn; sharing the love of a caring family; guiding them as they develop their personalities, interests, and talents; and teaching them justice and kindness—parenting can be simultaneously overwhelming and overflowing with joy.

Healthcare providers have a unique opportunity to offer guidance and support to individuals and families who are making decisions about their reproductive futures. Physicians and nurses can offer contraception to those who are seeking to avoid having children, temporarily or permanently. They can assist people who wish to get pregnant and have healthy pregnancies. They can care for those whose pregnancies are unwanted or unsustainable. They can care for those giving birth and care for the children who are born. And they can help when people aren't certain what the best path is for them at any given time.

A variety of frameworks exist through which to teach clinicians and others about the key ethical choices to be made in reproductive medicine. Each has its particular benefits and challenges, as will be examined within this chapter. Another framework, reproductive flourishing, will be added because of its utility in teaching reproductive ethics in the context of medical education and clinical practice.

Natural Law

A group of traditional, and commonly utilized, frameworks for addressing ethical questions in reproductive medicine use the idea of natural law to determine what is ethically permissible for individuals to use to have or avoid having children. The most prominent of these natural law frameworks is based in Catholic theology. With respect to reproductive medicine, this perspective is outlined in the 1968 papal encyclical *Humanae vitae*, which places strict regulations on what is considered ethically permissible in avoiding or seeking pregnancy.

Within the strictures of *Humanae vitae*, that which is not "natural" is disallowed for reproduction. For instance, the use of hormonal birth control for contraception is considered impermissible, as it intentionally interferes with the body's natural ovulation cycles. The timing of sexual activity to avoid a woman's most likely fertile days, on the other hand, is considered permissible because it does not directly disrupt the body's natural mechanisms. Likewise, the use of ovulation-enhancing chemicals is considered acceptable, as it is intended to increase that which occurs naturally. But moving fertilization outside the body, as in IVF, is not considered acceptable because fertilization cannot naturally occur outside the body.

The focus of the natural law framework is to provide guidance for what is and is not ethically licit to utilize in reproductive medicine among those who accept the framework's structure and rationale. It has been used to provide justification for social regulatory and funding structures, namely, for limiting the options that people have for contraception, abortion, assisted reproduction, and sterilization. But it provides no guidance on what the best choice is for any given person or family at a particular time, offers no help to those who do not accept its underlying assumptions, and has little to offer for other major decisions within reproduction outside of whether to use particular technologies to become or avoid becoming pregnant.

Reproductive Rights

The reproductive rights framework is grounded in an understanding of human rights that takes as its starting point the need for women, particularly, to be allowed a full range of access to reproductive technologies and choices in order to exist as social and political equals with men. The basic understanding of the reproductive rights framework has been stated by the United Nations' International Conference on Population and Development as:

> [Reproductive] rights rest on the recognition of the basic rights of all couples and individuals to decide freely and responsibly the number, spacing and timing of their children and to have the information and means to do so, and the right to attain the highest standard of sexual and reproductive health. It also includes the right to make decisions concerning reproduction free of discrimination, coercion and violence, as expressed in humans rights documents. (United Nations 2014, §7.3)

It is expressed in international documents like the Convention on the Elimination of All Forms of Discrimination Against Women, which has been widely, though not universally, accepted.

This rights framework is correlated to the natural law framework, in that both focus on what options for reproductive care should be available to individuals and their families, though the rights orientation focuses on minimizing strictures rather than providing them. It operates at a policy level as well, in arguing for why a wide range of options should be considered not only ethically licit but also readily accessible within the social and political structures of societies around the world. The rights framework postulates that human beings should be offered maximal reproductive freedom in order to achieve their personal values and goals.

The problems with this framework mirror those of the natural law framework. In focusing on what is licit and should be available, the framework does not offer guidance to individuals about how to make the decisions that are best for them. It also offers little to those whose moral beliefs fall outside of that system or who may have reservations about the goal of maximizing people's reproductive freedom. While it focuses on minimizing the potential constraints that people experience in exercising their freedom on a broad social level, it does little to guide clinicians in their care of their patients, as it functions as a set of universal norms, not specific to any given situation.

Reproductive Justice

The ethical framework of reproductive justice blends the concept of reproductive rights with that of social justice. Ross and Solinger (2017: 9) distill the framework of reproductive justice to three core principles: "(1) the right *not* to have a child, (2) the right to *have* a child, and (3) the right to *parent* children in safe and healthy environments." Drawing primarily on the lived experiences of African-American women in the United States, this ethical framework looks deeply at the underlying conditions in which people choose whether, when, and how to parent children. The developers of this framework argue that "all fertile persons and persons who reproduce and become parents require a safe and dignified context for these most fundamental human experiences. Achieving this goal depends on access to specific, community-based resources including high-quality healthcare, housing, and education, a living wage, a healthy environment, and a safety net for when these resources fail" (Ross and Solinger 2017: 9).

The ethical framework of reproductive justice provides important context in which claims on resources can be made in order to secure people's actual access to the rights identified in the reproductive rights framework. For instance, one of the reproductive rights claimed is that people should be allowed to decide whether to have (more) children, so sterilization cannot be made illegal. Reproductive justice takes that understanding a step further and considers the necessary conditions for the exercise of one's rights, such as having affordable access to health insurance and health plans that cover the sterilization option that fits one's needs best. This framework likewise takes into consideration past and present abuses in which people whose reproduction is looked upon unfavorably by society have been induced, and sometimes coerced, into sterilization and balances the right to be sterilized with the right to not be coerced into being sterilized.

Reproductive justice provides these important contextual factors and functions successfully at a policymaking level. Taking into account systems of bias and oppression helps significantly to ensure that the rights, dignity, and well-being of all people are also taken into account. Where reproductive justice falls short as a framework is at the level of individual decision-making and clinical guidance. It can make a much broader range of options open, but doesn't help individuals assess what may be best for them.

Reproductive Flourishing

The framework of reproductive flourishing begins from the same set of values that underlies the reproductive justice framework and moves it out of the level of broad social policy and applies it at the level of individual decisions in the context of interactions with clinical care providers. Where reproductive justice focuses on identifying barriers to high-quality care and ensuring real access to needed resources for parenting whether, when, and how one chooses, reproductive flourishing begins from the life stories of individuals and focuses on how to enact the person's deepest values, goals, and commitments in the area of reproductive decisions.

At its core, reproductive flourishing assumes a policy and ethical framework in which the rights of individuals are upheld and the need for a just and effective policy structure is available and then moves to the microlevel interactions and decisions that individuals and families make on a daily basis about whether, when, and how to parent children. The model of flourishing is offered to help clinicians give guidance to their patients for how to best decide for themselves what their lives should look like and to help patients navigate the murky waters of the healthcare system in ways that allow them to be and become their best selves.

A model conversation between a physician and a patient that uses the framework of reproductive flourishing would begin with the patient's own story: her goals, values, aspirations, and challenges, as well as her family and career, education, and other opportunities. The clinician would then assist the patient in determining what options best suit the narrative she has offered, and they would work together to help the patient meet her goals. Helping the patient to flourish, as her best self, is the primary ethical focus, which includes helping clinicians to flourish as their own best selves.

Case Study: AJ

AJ, 29, is a medical assistant who is married with 2 children, ages 2 and 5. She and her spouse both work full-time to pay their bills, including childcare for their children. The religiously affiliated hospital at which she works provides health insurance for the family but includes limited access to contraceptive options. She is meeting with her physician for her annual well visit and wants to discuss her options for avoiding pregnancy until her kids get older. AJ tells her doctor that she thinks an IUD would be the best choice for her over the next few years, but she can't afford the $700 upfront cost, much less afford to have another child at this time. How should her physician approach the conversation with AJ about her contraceptive options?[2]

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[2] Access to birth control without a co-payment has been guaranteed under the Patient Protection and Affordable Care Act; however, this is an area of law which has undergone rapid change. As of October 6, 2017, the US Department of Health and Human Services issued an updated rule, which broadly exempts employers who claim a religious or moral objection to providing contraceptive care from including contraception in their employer-sponsored health plans. The updated rules do not provide work-arounds for employees whose employers choose not to provide contraceptive coverage to obtain them directly through their insurers (Moral Exemptions and Accommodations for Coverage of Certain Preventive Services Under the Affordable Care Act, 82 FR 47838 (October 13, 2017), and Religious Exemptions and Accommodations for Coverage of Certain Preventive Services Under the Affordable Care Act, 82 FR 47792 (October 13, 2017). *Federal Register: The Daily Journal of the United States.* 13 October 2017).

Within the natural law framework, the advice given to AJ is fairly straightforward, though not particularly helpful. The natural law framework predetermines what AJ's options should be, and she may choose to limit the timing of her sexual activity with her spouse in order to attempt to not become pregnant for a time, but if this attempt fails, she is likely to become pregnant with a child she does not feel financially able to care for. There is no accounting for AJ's particular circumstances nor assistance offered in case things go wrong. Natural law frameworks offer her no help if she does not fully accept their account of morality.

A reproductive rights framework offers AJ a bit more, particularly in arguing that she has the right to choose whichever option works best for her. But absent a structure of healthcare financing that makes these options accessible, the right remains theoretical. Reproductive rights serve as a starting point to indicate that options should be available, but the framework offers no guidance about what might be ethically best in her unique situation.

The reproductive justice framework goes a step closer to identifying AJ's needs and substantively addresses the context in which she cannot afford either to have a child or to access the contraceptive option of her own choosing. This framework goes beyond arguing for an abstract and functionally inaccessible "right" and moves into considering the policy and social structures that serve as barriers to AJ getting the care that she needs. It functions effectively on this level of social policy but still does not offer concrete guidance for AJ and her physician on how to navigate her own needs and desires.

The reproductive flourishing framework utilizes the underlying structure of reproductive justice but moves the frame to the level of the individual. What does AJ need to flourish? Her physician can then use this focus to identify ways in which she can avoid having another child at this time, without imposing an external narrative on AJ that she herself might reject. AJ does not need to be told that she should or should not have another child; she needs to be able to talk through her core values and goals and be offered assistance to enact them. In this case, that may look like the physician offering a payment plan so that she can access an IUD affordably, alongside advocacy to help other patients like AJ afford the care that they need. It may look like talking through with her whether one of the forms of contraception that are covered under her health plan might work well instead. What does AJ need and want to accomplish, and how can we help her to become her best self, as a person and parent?

Teaching Reproductive Ethics

Each of the frameworks identified above has been utilized in teaching reproductive ethics to students who are in the process of entering clinical care fields, including medicine, nursing, public health, social work, and spiritual care. The natural law and reproductive rights models are the most commonly used, and they lead to specific challenges in teaching students.

As noted above, both models focus on what is permissible for patients to choose, not what may be best for a given patient. This emphasis on ethical permissibility tends to induce a conflict orientation in students who are learning to utilize the ethical frameworks. For instance, those who primarily utilize a natural law framework may argue with those who use a reproductive rights framework over whether abortion, assisted reproductive technologies, contraception, and the like should be permitted within a society.

Students move quickly into conflict orientations and strongly defend their ethical ground from those who disagree with them. Discussions of best practices in clinical care devolve into unproductive debates about abortion policy, with each side entrenched in their own deeply held position from which they do not listen to or empathize with one another. The conflict orientation leads students to think in zero-sum, win/lose terms, about disagreements over broad public policies. In addition to primarily raising emotions (and blood pressures), the focus on broad philosophical conflicts turns students away from the focus on serving their patients. It keeps them from addressing the real, everyday questions that they will face in patient care: how do I best serve the needs of this patient, talking to me now, with the real problems that she faces?

Using the ethical framework of reproductive flourishing helps to reduce the conflict orientation that students frequently experience when discussing ethical issues in reproductive medicine. Reproductive flourishing moves the focal point from the clinician's own beliefs about policy to the needs of the specific patient and her own beliefs and values. It allows clinicians to become more comfortable in working with patients whose values and priorities differ from theirs and helps students to address a wider range of topics in reproductive medicine than typically arise in the conflict framing.

This framework allows students to recognize and reflect upon the importance of reproduction in the context of patients' whole lives and requires them to think about all of the various ways that people need to flourish in the context of a whole life. It allows them to consider their own values, goals, and assumptions with regard to reproduction in a way that is safe and healthy as they strategize about how to best serve patients who present to them with unique challenges. It can serve to help build patient-provider relationships and teaches students to be worthy of their patients' trust, without automatically imposing their own views and values. The reproductive flourishing framework allows for pluralism of values without disregarding the values that clinicians bring to their encounters with their patients.

Using reproductive flourishing in teaching ethics in reproductive medicine helps center the discussion on the patient's story and deflates much of the emotionalism and entrenched conflict that often accompanies such discussions. The focus is set on the patients' particularity, context, and framing of their own values and decisions. But it is also adaptable for addressing the moral distress that clinicians sometimes experience, particularly when the values and goals of their patients conflict with their own or when they have to make difficult decisions about reproduction for themselves.

The individual narrative orientation of the reproductive flourishing framework also helps students move beyond the bare facts of a particular case and helps them to delve more deeply into seeing the situation from the patient's perspective. This moves learners further out of a conflict mode and into a position of needing to empathize with the challenges faced by their patients, perhaps especially in cases in which they may not naturally understand or identify with the concerns of that particular patient.

Case Study: Jessie and Chris

Jessie is a 34-year-old transgender man who comes to see you alongside his wife, Chris. They recently found out that Chris is infertile, and Jessie is interested in exploring fertility treatments so they can have a family together through him becoming pregnant. They looked into adopting but were unable to find a local agency that would work with them and are uninterested in working with a gestational surrogate.

In a conflict-oriented model, students might then focus on arguing about the respective rights of the couple to access certain healthcare services and the policy structures that make those services more or less available. But using the framework of reproductive flourishing, students are instead encouraged to explore questions with this couple to help identify and meet their needs, both individually and together. What does it mean to Jessie and Chris to become parents? How does the idea of Jessie getting pregnant impact their own understandings of their respective senses of gender and their roles within their relationship? How do Jessie and Chris each describe their journey toward parenthood? What has the impact of being declined by adoption agencies been on them? What sources of support do they have in working toward building their family? And what can the physician and healthcare team do to best support them and make them feel comfortable in the process?

This framework places the emphasis on the patients and how clinicians can best help them meet their needs for care and support in a way that minimizes students getting caught up in argumentation and entrenchment in established political positions. It allows students to learn about the real ethical issues faced in ordinary clinical care so that they can help guide their patients in making life-changing decisions.

Case Study: Maria

Maria is a 26-year-old Type I diabetic who is 24 weeks pregnant with her first child. At her current prenatal visit, Maria is found to have a blood pressure of 160/110 with proteinuria. She has been getting dizzy and vomiting for the past few days and is diagnosed with preeclampsia. The only available treatment for preeclampsia is the delivery of the fetus, and diagnosis of severe preeclampsia in the second trimester is associated with very high fetal mortality and maternal morbidity.

Cases like Maria's are unavoidably tragic, and using a framework of reproductive flourishing can help focus on meeting the patient's needs and goals as best as possible given the difficult circumstances. Students learning to use this framework can focus on eliciting the patient's own narrative in order to best serve her: What were and are her hopes and goals for this pregnancy? What sources of support can she draw on to help her through this time? This case comes with a very high likelihood of fetal demise; given that likelihood, what are her preferences for management of labor and delivery?

None of the other frameworks discussed above are particularly helpful in cases like Maria's. There is no question of naturalness or rights that can help Maria decide what to do next, nor does a framework of justice offer meaningful guidance in the face of tragedy. But focusing on offering trustworthy support to the patient guided by her values and goals can make a significant difference in how she feels supported and cared for in the worst of times.

The ethical framework of reproductive flourishing can be an effective tool for teaching students who are training to be clinical care providers to help their patients navigate through challenging decisions. By reducing students' orientation toward emotionally laden ethical conflicts in reproductive medicine, this framework can help students to better focus on the needs, interests, and values of their patients in order to provide them the best possible healthcare. While other ethical frameworks do a good job of addressing ethical questions on a broader policy level, there is a need for students to understand how these are translated into clinical care for individual patients, and reproductive flourishing can help meet that need.

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