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Honors Thesis Project Paper

The Importance of Language in the Discussion of the Ethics of Genetic Editing

While the availability of gene therapy and genetic editing procedures can't be said to be on a massive scale quite yet, with recent advancements in genetic technologies such as CRISPR-Cas9 the emerging possibility of human genome editing is increasingly on the minds of our collective discourse. Although, much like all ideas initially 'on the mind', the language of discourse has yet to be meaningfully applied beyond some early primordial musings. Though to some language might seem an minuscule aspect to focus on, in actuality it's perhaps the most important piece regarding emergent genetic technologies. While those technologies in of themselves possess the power to edit an individual's genome, the language of a society's discourse will be the deciding factor on how these technologies are viewed, on which conditions they will be used, and which subjects will be excluded. To that end, the topic of the usage of language to contextualize genetic editing is worthy of consideration in a discussion of ethics. It is also an end of this paper: to attempt to theorize how the topic of genetic editing might be approached in the future. This will be accomplished by first exploring how legal language, specifically that of the United States, might shape how genetic editing technologies are used. It will then address scenarios outside the window of legality such as questions regarding eugenics and other dystopian concerns, and finally conclude with an attempt to explore how experts and other relayers of information might communicate with the public regarding gene editing technologies.

Part 1: Gene-editing under the Legal Right to Parental Autonomy

When discussing the potential legal status of emergent gene editing technologies it is important to state in what purview these technologies act upon, and subsequently to which legal standards they would have to conform. Specifically, CRISPR-Cas9, with its applications to *in vivo* targeted genome editing in germ-line stem cells, cast itself as a technology relating to reproduction and thus is subject to the dictates of reproductive law (Horvath, 169). Given the relatively recent emergence of this technology, legislation and regulations specifically tied to genetic editing are few and far between. In its absence the focus will be placed on case law and the rights that stem from their corresponding verdicts, specifically case law pertaining to reproductive rights and parental autonomy.

Considering that in all likelihood, the decision to genetically alter an embryo's genome will lie with the mother that produced it, the issue of embryonic genetic editing lies on the right to parental autonomy: the ability of a parent to independently direct the upbringing of his or her child without the interference of societal and governmental institution. On this right to parental autonomy, U.S. case law has historically given the right a broad range of permissiveness. As early as 1923 in *Meyer v. Michigan* the U.S. Supreme Court gave specific form to the right to parental autonomy when striking down the state's statute banning the teaching of languages other than English before the eighth grade (Ossareh, 735). In the majority opinion, the Supreme Court justified their decisions by citing the Due Process Clause of the 14th Amendment claiming that the Due Process right regarded "not merely freedom from bodily restraint but also the freedom of the individual to . . . marry, establish a home and bring up children and generally to enjoy those privileges long recognized at common law as essential to the orderly pursuit of happiness for free men" (Ossareh, 736). Furthermore, the court continued to defend the definition of parental autonomy that they put forth in *Meyer*. For instance, the court cited the

Meyer decision in *Pierce v. Society of Sisters* (1925) that the statute in question "unreasonably interfered with the liberty of parents and guardians to direct the upbringing and education of children under their control when the statute had no reasonable relation to some purpose within the competency of the state" (Ossareh, 737). The court also followed similar reasoning in their ruling on *Wisconsin v. Yoder* (1972), citing parental autonomy in their decision to invalidate a state statute requiring Amish students to attend high school until age 16 (Ossareh, 737).

The previous three cases outlined did not attempt to make the right to parental autonomy seem absolute. Depending on whether an activity done by a parent is deemed worthy of state interest and protection, the authority of the parent in the upbringing of their child can be curtailed as in the case of *Prince v. Massachusetts* (1994), which saw a mother's religious beliefs come up against the state's interest in child protection (Ossareh, 738). But these types of rulings are exceptions to the general legal norm: a broad parental discretion on the upbringing of their child regardless of the benefits or detractions those decisions may have.

The right to parental autonomy has several implications in regards to the legal status of emergent genome editing technologies. For one, it would likely be regarded in the same way as other genetic technologies involved with procreation. Presently, it is common for those who undergo or contemplating pregnancy to preform genetic testing on their potential children. Prenatal genetic testing, via techniques such as chorionic villus sampling, allow up and coming parents to learn about the likelihood of any abnormalities developing within their children such as Down syndrome or cystic fibrosis and to subsequently decide whether to terminate the pregnancy (Brownsword, 310). Similar decisions can be made prior to implantation as well, with methodologies such as preimplantation genetic diagnosis (PGD) allowing those who chose to undergo *in vitro* fertilization (IVF) to assess the health of the embryos as well as the sex prior to

making a decision regarding which embryo to carry to term (Brownsword, 310). These technologies are largely legally unrestricted barring some safety regulations. Genome editing, though it differs in means, offers similar functions in terms of allowing parents to prevent harmful genetic traits regarding health from developing in newborns. Thus it is likely that as genome editing technologies continue to emerge and become more prevalent to the public they would be treated by the language of the law in a similar manner to current genetic testing technologies, a tool to be taken advantage of by parents due to their right to parental autonomy (Ossareh, 730).

This isn't to say that there would be no attempt to curtail legal access or an attempt to regulate in some capacity genome-editing technologies on either the state or federal level. As society adjusts to the availability of a new technology it will have a period of uncertainty in how it should regard it in the language of legality. But based on historic precedents and how present genetic technologies are regarded in the purview of reproductive rights, the treatment of gene-editing technologies would largely be that of free access and left to discretion of up and coming parents as due by their legal autonomy.

Part 2: Ethical Blindspots and Eugenicel Implications

Yet the linguistics of law and the language of ethics, though occasionally correlated, are not one-to-one. The legal right to parental autonomy doesn't begin to address the potential implications such emerging gene-editing technologies may have. Current gene screening

technologies involved in reproductive care such as PGD allow patients whom chosen method of implantation is IVF to select the sex of their embryo, a crucial aspect in the biological development of any child (Ossareh, 741). Yet the possibilities offered by emergent gene-editing technologies makes such a choice seem quaint in comparison. Gene-editing technologies will not only allow parents to make therapeutic adjustments to their future children as part of a medical treatment, though as shown later even this aspect is prone to moral quandaries, but select children with particular aesthetic and non-medical traits according to their own whims and desires. This selection by parents of perceived positive and beneficial traits via excising perceived negative and harmful traits in an effort to improve the person that might become their child plays into a sense of biological determinism: that genetic traits, above all else, decide a person's livelihood in all its aspects (Mathews, 733). Specifically it's a determinism that has historically informed various eugenics proposals, and it is this dubious idealogical relation that is most important as we shape the language of discourse around emergent gene-editing technologies.

Eugenics, if it can be concisely defined, is the belief that reproductive strategies can be used to improve a population in the capacity the believer sees fit (Roberts, 790). Though this brief definition fails to acknowledge the historical context in which these eugenics proposals appeared. Historically, "improve the population" meant reducing the births of socially marginalized people. In the United States, this took the form of multiple statutes in the early twentieth century such as the 1907 and 1924 sterilization acts in Indiana and Virginia respectively (Roberts, 790). These two laws allowed for criminal populations, disproportionally African-American and those confined to mental institutions to be subject to compulsory sterilization if the corresponding authorities saw fit to do so (Roberts, 791). Similar acts we

adopted through-out the U.S. up until the aftermath of World War 2 where the state would sanction, frankly, racially and mental-normally charged population control measures that further marginalized these groups (Roberts, 791).

It is here where the comparison between these eugenicel acts of the past and the potential usage of these new gene-editing technologies is not entirely one-to-one, as noted by figures such as British sociologist Nickolas Rose. The acts fuel by eugenics in the early twentieth century were a bio-political strategy that sought to use deliberate state action as a means of population control (Handwerker, 117). The usage of both contemporary PGD and emergent gene-editing technologies, however, are not legally compulsory. It up to parental discretion how and to what extent these technologies serve as part of a reproductive selection process (Handwerker, 118). The onus is then on the parent, motivated by a desire for self-fulfillment and the wish for the best life of their child, to make these genetic changes. Instead of a politics of marginalization, Sociologists such as Rose claim that it is "a bio-politics concern with the genetic health of individuals" (Handwerker, 119).

While the distinctions scholars like Nickolas Rose make between eugenics proposals of the early twentieth century and the likely contemporary usage of new gene-editing technologies are important to acknowledge, to what extent they separate the selection these technologies instill from eugenics is still questionable. Yes, the onus has been privatized to an individual's decision, but it doesn't necessarily follow that the endpoint has been changed. At the core of eugenics thought is the attributing of social inequities to reproduction and genetic traits rather than social structure. If parental decisions regarding their child's genetic are made under this pretense it is still a form of eugenics, just on a micro-level rather than on a macro-scale.

With this in mind, let's approach the usage of genetic technologies for medically therapeutic reasons. These technologies seek to alleviate genetic abnormalities such as those associated with Down syndrome and cystic fibrosis. While at first glance this is a relatively benign usage of the potential offered by gene editing, there does exist moral nuances that serve to muddle the issue. Specifically, the issue of what genetic abnormalities should be considered for medical treatment. While some would certainly be easily applied to that list such as cystic fibrosis, some conditions have more problematic implications if they were put on this hypothetical list. Say there is an embryo with a trisomy on the 21st chromosome, meaning that in all likelihood if that embryo develops into a child he or she will exhibit Down syndrome. The child will have a intellectual disability; will be physically abnormal and possibly develop hearing, visual problems, or other health issues stemming from this syndrome. Gene-editing technology could serve as means of resolving the trisomy and thus remove the chance of developing down syndrome for that child. A similar selection already exists with people opting into pre-natal screening and PGD, with a parent having the option to discard the fetus/embryo with this syndrome (Roberts, 794). The implications are shared as well: that people who possess down syndrome or other innate, easily identifiable disabilities are better off not existing in the first place. The decision to discard the embryo falls in line with eugenics thought, that rather than a society taking up the initiative to accommodate this individual any difficulties this individual may have must be shouldered by him alone and the parent that chose to begat him (Roberts, 795). The nature of the choice "reinforces a model that disability itself, not societal discrimination against people with disabilities, is the problem to be solved" (Roberts, 794).

There also exist the issue of to whom these genetic technologies are advertised and in what way. While novel technologies like gene editing would likely be first concentrated into the

hands of those with enough monetary and financial resources to afford them, as the field develops and grows more prevalent these treatments will increasingly become available for the general public to take advantage of. This opens up some disturbing possibilities, specifically in how these technologies are marketed to minority groups and the subsequent implications. The pharmaceutical industry, for instance, has already opened the door for specific marketing of drugs to members of specific social groups (Cahill, 15). The Food and Drug Administration in June 2005 gave approval to the company Nitromed's novel drug BiDil, to treat heart failure specifically in African American patients (Roberts, 786). Chemically, BiDil is a combination of two generic medicines already in use by doctors to treat heart-related issues in patients regardless of race (Roberts, 786). Despite this fact, the FDA nevertheless gave permission to Nitromed to market it specifically as a drug for African-American people under their questionable theory supporting the need for a race-specific therapy which states that the reason for higher mortality rates among black heart patients lies in genetic differences among "races," in either the reason for getting heart disease or the reason for responding differently to medications for it (Roberts, 786). Dubious marketing and patents such as this perpetuate a biological definition of race which explain social inequities racial relations as not the result of history and social structures but as natural. Given that race-specific targeting has already begun to appear in contemporary areas of medicine such as pharmaceuticals, there is a chance that gene-editing technologies will also be targeted to specific racial groups using a faulty biological understanding of race. In other words, eugenics ideas might be communicated and perpetuated via marketing.

These two aspects of the issue are why despite the privatization of the decisions, genetic-editing techniques when coded to the common language of contemporary society can serve eugenics ideology. While the means may be different from state sanctioned campaigns regarding

population control in the early twentieth century, the eugenics iota of justifying class, race, and other social hierarchies as part of the natural order continues to be the ending consequence. A viewpoint that is not only repugnant from an ethical standpoint but is also unscientific with research done with the Human Genome Project determining that social races are more genetically divergent within their populations than the variation between racial groups (Harris, 357). The distinction that sociologists like Nickolas Rose make between the state-sanctioned eugenics of the twentieth century and the private choice of parents should not be one that excise the eugenicel implications when applying the common language of contemporary discourse. Instead the distinction merely encompasses how the notions of biological determinism were conveyed and implemented in two different eras of a society: one where the legal rights of socially marginalized people were less recognized and overt racism more tolerated, and another where overt displays of racial prejudice are looked down upon and the machinations of neoliberal capitalism are the norm.

Part 3: Shaping the Emerging Discourse

This is precisely why shaping the language that contextualizes these new genetic technologies and how the discourse surrounding these techniques are facilitated is of upmost importance as these gene-editing technologies become more prevalent. Without careful consideration of how we shape the discussion around these new technologies, the usage of gene-editing might help facilitate and reinforce not only scientifically false and ethically questionable biological definitions of race, but also hinder attempts to accommodate disabled individuals in society. Many genetic counselors are often very directive when discussing with their patients

about the option to preform a selective abortion or discard an genetically abnormal embryo. For example, a survey done by Dr. Brian Stotko reported that many of the 985 participants who received pre-natal diagnosis of Down syndrome for their children were chastised by health care professionals for not making the decision to abort (Roberts, 785). Furthermore, there is a need to bridge the gap between lay people's perspectives on emergent gene-editing technologies and the viewpoints of experts feverishly working on making these technologies possible. Often lay people are less aware of the mechanics of gene editing and often express concerns over how such technology are used. A focus study preformed by Ian Barns found that the participants, while not out right rejecting the possibilities of gene-editing technologies, nevertheless expressed some concerns; specifically in areas involving what traits are targeted for editing and the motivation behind such decisions (Barns, 290).

Developments are already taking shape into guiding the shape of this discourse in a way to avoid the eugenicel implications and the divide between the public and experts understanding of these emergent genetic technologies. An experiment preformed by Robyn Shaw explored avenues on facilitating discussions between interested lay people and experiments. With the use of a community consultation workshop they were able to craft a forum in which lay people can express their questions and concerns to experts and they in turn sought to address them (Schibeci, 338). Granted that workshops such as these are limited in their scope and aftermath; the model nevertheless proved useful as a proactive tool in establishing communication between the scientific and medical communities and the larger set of public interests (Schibeci, 338). It also has proved to be an effective tool in the process of policy formulation as seen in the review period of the Western Australian Reproductive Technologies Act in 1998 (Schibeci, 338). Meanwhile genetic counselors, though they might differ in practice, are technically under oath to

be non-directive in the treatments of their patients. The key in this is to frame the discussion of innate disability not just in the form of the choice to discard or not but rather attach to the latter options resources, both governmental and NGO, to allow parents to care for a disabled child should they decide to carry the pregnancy to term.

The difficulty in discussing the emergence of new technology and the implications it may have is that it is largely intangible to reality, therefore any attempt to theorize how these technologies might be contextualized in the broader society is dependent on speculation based on current societal trends. This limitation in mind, given recent medical, marketing and other societal trends, the emergence of gene-editing technologies will carry with societal implications of a eugenicel nature. To prevent such ideology from taking hold of the public's imagination, it is imperative that clear communication is established between lay people and the larger scientific and medical community so concerns can be addressed and the more disturbing aspects that might emerge with gene-editing technologies can be circumvented and adverted.

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