The Co-Evolution of the Permissibility of Genetic Engineering and Parental Obligation

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Background

Gattaca, Andrew Niccol's popular 1997 science fiction film, explores the role genetic engineering is projected to play in the not-so-distant future within the realm of bioethics. The film begins by introducing both sides of the ethical debate through the opening credit, "Consider God's handiwork; who can straighten what he hath made crooked?" (Ecclesiastes 7:13), which is immediately followed by "I not only think that we will tamper with Mother Nature, I think Mother wants us to" (Gaylin, 1984). Niccol explores the impact genetic engineering can have on various aspects of life, such as family planning, new forms of discrimination, and understanding of self-worth and capabilities, in a world deeply immersed in technological advancements. While the prospects posed by *Gattaca* may have, at one point, been dismissed as purely a figment of science fiction, we are now in an era in which we must critically evaluate the permissibility of genetic engineering in future persons.

This paper will be examining our evolving attitudes towards gene editing in three categories: aesthetics, non-fatal disease prevention, and fatal disease prevention. Since matters of selection for future persons often involve parental decision-making, this paper will analyze the evolution of attitudes through the lens of our developing understanding of parental responsibilities. With the expansion of human genome editing, we will soon need to find answers to a multitude of ethical concerns. By having this ethical discussion, we can pave the way towards equitable policy-making that protects genetic diversity and honors the autonomy of future persons.

Gene Editing

In this section, I will introduce and define gene therapy, differentiate between the different types of genetic engineering, and highlight the mechanisms by which it is accomplished. Gene therapy is known as any practice designed to favor the expression of "desirable" genetic traits and/or curtail the expression of "undesirable" traits. Genetic editing falls under two main categories: somatic gene therapy and germ-line therapy. This paper will focus on the possible applications for these therapies, which involve aesthetic-based modifications, non-lethal disease prevention, and lethal disease prevention.

A. Somatic Gene Therapy

Somatic gene therapy is conducted on somatic, also known as body, cells. This therapy does not affect reproductive cells, and therefore, any alterations made are not passed on to future generations (Patterson, 1999). This therapy is often the one discussed when considering enhancing an individual's traits. Somatic gene therapy, for example, could be used to extend the lifespan of cystic fibrosis patients by editing the faulty gene that causes excessive production of abnormally thick and sticky mucus that damages the lungs – which currently cannot be addressed by existing drug therapies (Patterson, 1999). While applications such as these can prolong and improve the quality of life one has, there are also concerns that this technology will result in enhancements that serve purely aesthetic motives, such as choosing the physical traits of your offspring. While some dismiss these worries as being unfeasible due to the multigenetic nature of traits, such as eye color, height, and temperament, Patterson argues, "The rapid identification of genes affecting physical and behavioral traits coupled with improved methods of injecting genes into humans will make genetic makeovers possible."

B. Germ-Line Therapy

Germ-line therapy involves editing genes in reproductive cells making any changes heritable for future generations (Patterson, 1999). Many critics denounce this form of gene therapy because "Individuals have the right to select the genes they want for themselves, but cannot impose that on others" (Patterson, 1999). While some argue that enhancements could only ever be a positive gain for future persons, many scholars highlight that some edits could be defective, resulting in fetal demise or traits that make a child worse off. Even when edits are executed properly and result in trait enhancement, "parents might have un-realistic expectations of children who have been subject to efforts to make them superior" (Patterson, 1999). While traits may be enhanced, the dynamic of the parent-child relationship may face additional psychological strain through lower self-esteem in children and higher, unrealistic expectations in parents.

C. Mechanism

Both forms of genetic therapies are mediated by a popular process known as CRISPR (clustered regularly interspaced short palindromic repeats). As described by the NIH, CRISPR is a technology that “allow[s] genetic material to be added, removed, or altered at particular locations in the genome.” The process involves creating modified RNA that is used to recognize a specific DNA sequence, which is then cut by the Cas9 enzyme. Once the DNA is cut, researchers add or delete pieces of genetic material, or replace an existing segment with a customized DNA sequence.

Bioethical Principles

Before introducing the role of parental figures play in the decision-making process for their children, we must first define and discuss the role of bioethical principles in order to promote ethical policies. Bioethicists must consider four basic principles when determining the permissibility of a medical treatment: autonomy, beneficence, non-maleficence, and justice. Ideally, for a practice to be considered "ethical," it must uphold all four of the principles. However, in practice, two principles may come into direct conflict, thus, forcing a bioethicist to determine the principle that best promotes ethical decision-making. While this paper recognizes the valuable and necessary role each principle has in the discussion of gene editing, I will argue that our priority as moral agents is to focus on upholding autonomy of future persons and creating policy promoting equitable policy-making. Although non-maleficence and beneficence are invaluable, their application is often promoted and upheld through current research and medical policies.

A. Autonomy

Autonomy describes the right or condition of self-government, that is, one acts in accordance to their objective morality rather than under the influence of desires. Autonomous individuals should be able to act intentionally, with understanding, and without controlling influences that would mitigate against a free and voluntary act (Gillion, 1994). Lastly, the autonomy of one individual may not be used to suppress the autonomy of another individual. The importance of this principle in the medical field is evident through the extensive promotion of informed consent.

B. Beneficence and Non-Maleficence

Non-maleficence requires us to avoid intentionally creating harm or injury over others, either through acts of commission or omission (Gillion, 1994). While this principle recognizes that erasing the possibility of harm may not be possible in some instances, it requires moral agents to reduce potential harm as much as possible.

Beneficence describes the duty one has to maximize and promote good onto other individuals (Gillion, 1994). While both of these principles are distinct, they are often considered together when health professionals are making medical decisions. The act of limiting harms and promoting goods is part of an essential cost-benefit analysis used to provide patients with the best possible health outcomes.

C. Justice

Justice describes equal distribution of both the burdens and benefits of decision-making among all groups in society. A health care provider must, therefore, consider fair distribution of scarce resources, competing needs, rights and obligations, and potential conflicts with established legislation (Gillion, 1994). Technologies, such as gene therapy, create ethical dilemmas because the treatments are not equally available to all people, usually due to financial cost.

The Role of Parental Obligation in Selection

In the discussion of gene therapies, the role of parental obligations and rights is essential due to the limited autonomy children have when they are minors. Since parents are expected to play the role of an autonomous agent for the first 18 years of a child’s life, we must therefore understand what qualities a parent values in medical decision-making, what they perceive as their duty to their child to be, and how these behaviors have changed over time and why.

Our understanding of parenthood varies greatly due to a variety of aspects, such as cultures and generational differences. Therefore, as bioethicists and medical practitioners, it is our responsibility to be sensitive to those differences in order to meet a parental decision-maker at their level and effectively advocate in favor for the most beneficial choice for their child.

In Western society, there has been a major and significant shift in our understanding of parenthood due to the rise of feminism and the role contraceptives play in family planning. As highlighted by Steven Mintz, "The decision about whether or not to have children is voluntary. Electing not to have children is no longer stigmatized in the way it was. "Child-free" adults are no longer casually dismissed as shallow and self-absorbed" (Mintz, 2015). Contraceptive technologies and shifting attitudes towards the reproductive obligations of young adults have made the family-making process a more debilitate and purposeful one. Rather than abiding by societal expectations as before, individuals now have the resources and social support to choose when, or if, to procreate. These changes in attitude are further supported by previous notions of parenting.

Previous Philosophies

Before family-planning was truly a choice individuals could make for themselves, the understanding of parenthood was much different compared to our current notion. Previously, proprietarianism, which describes "children as the property of their parents" was well adapted into our society (Austin). Proprietarianism gained large traction because it simply seemed logical that parents own their children as they did any other form of property, since in some sense, they produced them. This notion was further supported by the understanding that "parents own themselves, including their genetic material, and since children are a product of that material it follows that parents have rights over their genetic offspring" (Austin).

However, critics of proprietarianism reject this ideology because it is immoral to reduce children to property and remove their human status. Children are human beings, and as such, cannot be owned by another human being, regardless of an existing genetic connection. The critics of proprietarianism rely on arguments that align with the first bioethical principle, which is autonomy. Critics recognize that a parent cannot use their autonomy to erase the autonomy of their child because, at some point, that child will become a fully autonomous agent themselves. Allowing parents to use their autonomy to override the autonomy of their child through the use germ-line gene therapy, for example, to change a trait in their child results in forever closing a door for future persons who may have never consented to such a change in the first place.

Critics of this ideology extend this argument by showing that treating a child as an object changes the dynamic of the parent-child relationship from a familial one to a commercial one. This is harmful because it "transforms children into manufactured products, which we design rather than receive" (Austin). When considering genetic engineering, proprietarianism values the desires of a parent over the effects a decision has on the future child. As presented by Austin, "ideally, at least, parental love for children is to be unconditional, but in cases where parents choose the gender of their offspring it may be that their love is already contingent upon the child having a certain trait." This is problematic because genetic engineering introduces another unavoidable and naturally-occurring issue: genetic obsolescence. Genetic obsolescence is understood as planned obsolescence for genetic engineering, meaning that consumers will never be satisfied with the changes made and will always be in search of the next best thing. This is best seen in the automotive industry. Different models of cars are produced every year and quickly become devalues and obsolete as consumer preferences and demands evolve. This behavior is already seen in body modifications because "improvements on the human design to make a better product through body modification enhancements ranging from tattooing and skin-whitening creams to aesthetic surgery such as Anglicizing nose jobs, to facelifts and more recently vaginal rejuvenation surgery in the restless search for new flesh to remodel. The promotional language of getting your "first" tattoo or facelift registers the iterative dimension of obsolescence that moves consumption forward," a behavior which would only be amplified by ideologies such as proprietarianism, which transform individuals into products to be designed and modified (Garland-Thomson, 2019)

Although proprietarianism's popularity and acceptance has dwindled down, it is important to highlight that the permissibility of genetic engineering for aesthetic reasons would allow this dangerous and unethical ideology to flourish once again. Genetic engineering purely for aesthetic purposes will be accepted as just another form of body modification, which will never result in complete satisfaction and promote the commercial relationship between parent and child.

Current Philosophies

Now, due to the variety of choice many individuals have access to when deciding to make a family, being a parent is not an imposed duty as it used to be. When adults choose to be parents in this age, it is a purposeful and deliberate decision, thus resulting in the legal obligations was see today. Michael Austin, a co-author of Internet Encyclopedia of Philosophy, describes parental figures for children to be agents who "want them, love them, and desire what is best for them, regardless of whether a biological connection exists." In terms of legality, this means parents are obligated to serve a child's emotional and physical needs and protect the child from abuse. While these definitions and guidelines might seem simple, there is ample evidence that parents struggle with its actual application because "parents have grown far more sensitive to the risks that their children face, both physical and psychological" (Mintz, 2015). With an overwhelming amount of freedom and excess of outside resources/suggestions, parents suffer from constant anxiety over making the wrong decision for their child. Such anxiety results in a knee-jerk reaction from parents pursuing the absolute best for their children, which may blind them from the negative effects such pursuits may bring.

Before a child is even born, prenatal testing leads parents to worry about potential birth defects, an anxiety which was not even present in the past. With gene therapies on the rise, these anxieties can result in parents advocating on behalf of their child with very limited medical and scientific knowledge. In order to mitigate purely emotional and passionate decision-making, it is the role of a bioethicist to lay the foundations of what is ethically permissible in gene therapy and what policies would best endorse the future health of both the parent and child.

In order to begin establishing this, we must first come to a mutual understanding over what is truly expected of parents. Bioethicists, such as Laura Purdy, argue that parents have a duty to provide their children with a "minimally satisfying life." Since there is variation in what is considered "satisfying," Purdy argues that this phrase shall only be extended to health concerns, meaning that parents are obligated to provide a child with normal health, which can change among cultures. Scholars promote this idea because conception, now more than ever, is under the control of the parents. If a child is projected to suffer and live a lower-quality life, it is then morally permissible to abort or conduct somatic gene therapy because both of these options only affect the fetus. Additionally, Purdy argues that parental freedom, choices, and desires are all limited by their duty to provide their children with a minimally satisfying life, meaning that genetic engineering in not permissible when using it to pursue parental desires due to the harm it can impose of the future child.

Purdy's philosophies are prominent in the discussion of ethical gene therapies because they promote the idea of putting children's safety and well-being first. This is especially valuable when discussing the permissibility of gene therapy because it ensures that a child will not be reduced to a singular trait. For example, the expressivist argument states that selection promotes discriminatory attitudes towards people living with disabilities and reduces them from a person to just their disability (Parens, 1999). Both of the philosophies are important when establishing what is permissible because it extends humanity and empathy to populations that are often ignored. Therefore, gene therapy in order to undo a disability that is medically actionable, does not reduce the quality of life for an individual, or is not lethal is not a valid or ethically permissible because it undermines our understanding and inclusion of vulnerable populations, such as the disabled community.

Additionally, both Purdy's and Parens's philosophies call for parents to assess what motivates them to become parents in the first place, and question why that motive is contingent on specific traits that do not change the value of parenting that child. As the rise of gene therapy continues, it will soon be accepted as a logical extension of good prenatal care. Parens's parental attitude argument states that selection entails a problematic understanding of the attitude towards parenthood and parental roles because the particular traits of children should not matter (Parens, 1999). Philosophers now argue that the role of a parent is to nurture the children they end up with because selection of traits that are not medically necessary for children results in commodification and treats children as a means to parental satisfaction rather than ends in themselves.

Making Medical Choices

While we may currently lack sufficient data to analyze how these philosophies impact real-world parental decision making, various hypothetical situations have been posed to parents to measure what they currently deem as ethically permissible. Cary Frank conducted multiple surveys in 2016 assessing the permissibility of CRISPR technologies in Western societies. Frank found that 68% of U.S. adults deem preemptively editing the genes of healthy babies to reduce the risk of other illnesses as a major worry while 73% of U.S. adults worry that the advent of gene editing could lead to widespread negative consequences for society. A majority of adults expressed that they worry this technology will be practiced before it is fully medically understood and that it would result in the promotion of inequality due to lack of access. Additionally, U.S. adults feel that using this technology to make a person far healthier than any human known to date would be taking the technology too far (54%) and that it is less acceptable if the effects changed the genetic makeup of the whole population (49%). Interestingly, however, this same study found that individuals who were educated on gene editing prior to the study, or had at least some exposure to understanding it, were more inclined to want it for their child (57%) as opposed to people who learned about it during the study (37%). This same educated population also expressed that they believed that benefits would outnumber the downsides of this technology.

The results of Frank's study have multiple interesting implications. These numbers show that U.S. adults are conservative in what they deem is medically permissible for gene therapies and that they are rightly concerned that their worries do not align with the rapid progression of the technology and lack of policies monitoring its use. Additionally, it shows that in order to have parental philosophies align with this novel technology, it is our responsibility to educate the public in a way that is both accessible across demographics and still scientifically accurate.

An additional study that measured the values parents upheld when making decisions for their children who were diagnosed with chronic conditions (cardiac, respiratory, genetic, neurologic, metabolic, malignant neoplasm, renal, and other) found that parents value decisions that ensure their child feels loved, focus on the child's health, and are based on informed medical decisions (Feudtner, 2015). All of our current studies conclude to similar findings, which is ensuring medical professional, scientists, bioethicists, and policy makers make a greater effort to understand the values parents have placed on decision-making for their children in order to support them when confronting difficult medical decisions.

Current Policies

While there are currently policies in place to protect individuals from genetic discrimination, there is still a necessity for more specific policy making that ensures inclusion and protection of future persons. As of date, policies such as GINA (Genetic Information Nondiscrimination Act) states that genetic information cannot be used by employers or health insurers (NIH, 2020). While this protects asymptomatic individuals, who may be carriers of specific alleles, it does not do enough to protect those who one day may not have access to gene therapies as it does not apply to life insurance, disability insurance, long-term care insurance, U.S. Military, or employers with less than 15 employees. Genetic discrimination “occurs when people are treated differently by their employer or insurance company because they have a gene mutation that causes or increases the risk of an inherited disorder” is still a rampant problem that must be addressed.

As genetic therapies become more available, various entities will expect individuals to genetically engineer themselves, or their offspring, which is inevitable due to the power these therapies naturally give to the concept of genetic determinism. According to the American Psychological Association, genetic determinism is “the doctrine that behavior and mental activity are largely (or completely) controlled by the genetic constitution of the individual and that responses to environmental influences are for the most part innately determined.” While the role of the environment on the expression of our genes has time and time again been proven to be existent and significant, gene therapies will inevitably promote genetic determinism, especially as we continue to decode and identify which genes influence which traits. As depicted in the movie *Gattaca*, this has the potential to become all-consuming in our society and runs the risk of disenfranchising those who did not have access to this technology. Additionally, the movie does an excellent job of portraying the maladaptive role genetic determinism plays in self-value. Jerome, the character who was designed to be the definition of physical fitness attempts to commit suicide when he places second in a race because of the strong notion that he could not improve beyond his current state despite the rigorous selection conducted to make him.

Future Directions

In order to make gene therapy as equitable and beneficial as possible, I advocate for following the recommendations outlined by U.S. National Library of Medicine in 2017. These recommendations state that genetic engineering is permissible when: there is an absence of reasonable alternatives; restricted to preventing a serious disease or condition; restricted to editing genes that have been convincingly demonstrated to cause or to strongly predispose to that disease or condition.

Additionally, these recommendations call for ongoing rigorous oversight during clinical trials; comprehensive plans for long-term, multigenerational follow-up that still respect personal autonomy; maximum transparency consistent with patient privacy; continued reassessment of both health and societal benefits and risks, with broad ongoing participation and input by the public; and reliable oversight mechanisms to prevent extension to uses other than preventing a serious disease or condition.

Additionally, in order to ensure the equitability of gene therapies, it is the responsibility of researchers to overcome barriers to minorities' participating in and benefiting from research they prioritizing diversity in genomic sequencing, building trust and partnerships, and advocating for equitable access to emerging therapies (Hildebrandt, 2018). By ensuring the diversification of genomic sequences, we will be able to produce more relevant research and clinical applications, and foster a sense of trust among historically oppressed and neglected communities.

Conclusion

In summation, with the rise of genetic therapies, it is important for policy makers and medical practitioners to understand parental motives and obligations and how they evolve over time in order to better communication and best advocate for the patient at hand, which will more often than not be a child who cannot yet consent. In order to best uphold all of the bioethical principles, we must only allow approval of genetic engineering that addresses lethal illness and disease that result in a low-quality life that cannot be significantly supplemented to fit our current able-bodied world. We must therefore reject genetic engineering when it pertains to non-lethal diseases that cannot be accommodated significantly, purely aesthetic modifications, and engineering that undermines the autonomy of future individuals (germ-line engineering). Additionally, it is the role of the scientific community to educate the general public concerning the new technologies that will soon become widespread in order to ensure that individuals can truly act as autonomous agents when making medical decisions that will have long-lasting impacts.

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