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Designer Babies: A Phenomenological Study on Genetic Engineering

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Literature Review

CRISPR and its Application

Currently, CRISPR, a revolutionary practice in genetic engineering, is primarily confined to clinical studies due to uncertainty about its long-term effects in biomedical research. CRISPR, short for *Clustered Regularly Interspaced Palindromic Repeats*, is a gene-editing technology that allows researchers to correct errors in the genome. The process gives the ability to turn genes on or off in cells and organisms quickly, inexpensively, and with relative precision (Redman, 2014). However, while the concept may appear straightforward, the execution is far more complex. For example, researchers recently attempted to edit the beta globin (HBB) gene, which affects blood cells and is most commonly associated with sickle cell anemia. Using CRISPR/Cas9 as "molecular scissors", they targeted HBB to cut specific sections of single-stranded DNA, creating a corrected copy of the gene without mutations. This strategy succeeded in only 4 of the 86 embryos that the researchers attempted to edit. The researchers also found that the molecular scissors snipped other genes that the researchers never intended to touch (Saey, 2015). In addition to Redmans research, she highlights that clinical studies have already demonstrated CRISPR's ability to repair defective DNA in mice, effectively curing them of genetic disorders. This success suggests the potential for similar modifications in human embryos. Beyond correcting genetic mutations, CRISPR is being explored for various clinical applications, including gene therapy to treat cancer and other diseases such as Duchenne muscular dystrophy (DMD) and haemoglobinopathies (Redman, 2014). While CRISPR holds immense promise, it also carries significant risks. The unintended consequences of genetic editing remain poorly understood, raising concerns about unforeseen biological impacts. Furthermore, the ethical challenges surrounding this technology are profound and complex, sparking debates that society is still grappling to comprehend.

Moral Perspective - Introduction

The consequences of gene editing remain uncertain, and even beyond clinical practices, there will always be an element of precariousness in its application. Selective termination or the elimination of an embryo is a decision that many expectant mothers are pressured into making when an abnormality or structural restriction is identified, particularly given that genetic engineering is not yet available to the public. An embryo can be defined as an unborn or unhatched offspring during the period from approximately the second to eighth week during fertilization, after which it is typically referred to as a fetus. Deciding whether to proceed with a pregnancy, knowing the potential for an illness, disease, or condition, as well as the economic, social, and physical hardships that could follow, could be a challenging decision. With the advent of new technologies to reverse or mitigate the effects of such conditions, many are quick to conclude that genetic modification is the only solution. Those desperate for a solution may be vulnerable to overestimating the benefits of early-phase studies while underestimating the risks, a phenomenon often referred to as the "therapeutic misconception" (Desine, 2020). Looking beyond the surface, decisions made during this process can carry a variety of complex repercussions. As a person grows, their self-conception could be profoundly affected by the knowledge that their genetic makeup was intentionally altered. Gene editing applications will also be used as an approach for addressing genetic variations based on typical ability expectations but it will expand into the area of generating "new" or "improved" abilities (Wolberg & Diep, 2016). While the primary goal of genetic modification is to reduce the risk of inherited mutations and illnesses like cystic fibrosis, the technology could also be used to edit DNA for specific, non-medical desires, introducing a new realm of ethical debates. Religious perspectives and moral arguments are among the most commonly raised objections, particularly as editing for desired traits could be perceived as undermining the legitimacy of genetic engineering itself.

Religious Perspective

"Playing God" or assuming the role of a divine creator is a significant ethical boundary for many when it comes to influencing the course of human life. For some, allowing the body to follow its natural course and addressing the outcomes as they arise is considered a more acceptable approach. This perspective raises an important question: do specific religious affiliations perceive gene-editing technology differently, or is the perception of gene editing influenced more by an individual's religious upbringing than by formal religious teachings? However, Alexander Massman, whose expertise lies in theology and theological ethics, highlights Christian advocates who place a high value on physical functioning, emphasizing the care of the body as a sacred creation. While the pursuit of higher functioning- defined here as enhancing the body's natural strength beyond its inherent capabilities- is often justified in the name of autonomy, many Christian theologians reject the maximization of physical functioning. Instead, they emphasize the religious significance of life's meaningfulness, even amid suffering (Massmann, 2019). In this context, suffering does not necessarily refer to physical affiliation but also includes experiences that differ from societal norms of physicality. Within Christantly, Massmann notes the concept of redemptive suffering, particularly as exemplified by Christ. Similarly, in Buddhism, suffering is central to understanding liberation, achieved through mindfulness and detachment. The irony lies in how religious frameworks that value autonomy simultaneously impose strict standards on whose autonomy is prioritized and how it is exercised. This paradox can alienate individuals who perceive the church as exerting control while selectively promoting autonomy for enhancements aligned with specific agendas. Massmann also draws on the work of philosopher Philip Kitcher, who critiques the use of a liberal account of autonomy in genetic engineering debates. Kitcher argues that a child's autonomy is a critical reason why cloning is ethically indefensible. He suggests that clone-parents would likely constrain the child's in her life choices, even though the actual influence of genetic traits on the child's future characteristics cannot be fully predicted. He fears that to 'enhance' children would lead to 'a rat-race for creating perfect people'. In this view, the child's autonomy should take precedence over the parents'. However, Kitcher points out a contrasting attitude when an embryo is diagnosed with disability: ‘parents who find the risk of a low-quality life [of the child] too great will be moved to abort’. A disability is perceived to reduce both a child’s and parents’ autonomy, so even a mild form of Down Syndrome can justify abortion (Massmann, 2019). The ideas presented by Massmann and Kitcher have significantly shaped discussions about the intersection of religion, autonomy, and genetic engineering, inspiring further exploration of how religious beliefs influence attitudes toward this technology. It is important to recognize that some ideas within these religious contexts may reflect ableist perspectives.

Ethics from a Parental Perspective

The ability to influence aspects of a child’s genetic makeup before birth represents an unprecedented possibility for many. This decision extends far beyond personal pride or recognition, as it deeply impacts the life of the child and raises profound ethical questions. The choices parents make regarding genetic modification carry significant transformative effects on their families. Many parents are drawn to CRISPR technology, a tool that allows for precise genome editing in virtually any organism (Doudna & Charpentier, 2014). CRISPR offers families relief through germline modification, as it eliminates the need for treatment of preexisting or developing diseases in their offspring or subsequent generations (Wolbring & Diep, 2016). However, the ethical line between eliminating genetic conditions and enhancing one's abilities remains a contentious issue. Parents who choose gene modification must grapple with the uncertainties about their child's future, creating significant ethical dilemmas. Consider a hypothetical scenario: A parent knows they carry a gene associated with a serious condition. Despite the heightened risk of passing it on, they choose to conceive without pursuing genetic modification- whether due to personal beliefs or a lack of available technology. Their first child is born with a congenital condition. Despite this, the parents dedicate themselves to supporting the child financially and emotionally. After a couple years of acclimating to the routine of caring for a child with medical needs, they decide to have another child, knowing the risk remains high. To their surprise, the second child is born without any genetic conditions. Could this difference in circumstances affect the sibling relationship in ways such as fostering envy or other complex feelings? How might CRISPR, and the societal emphasis on “fixing” genetic conditions, shape the self-perception of individuals with disabilities? Could it lead them to question their inherent worth or feel devalued by a society that prioritizes genetic “normalcy?” Additionally, when parents pass away, the child with a disability may rely heavily on the care and decisions of their able-bodied sibling. This responsibility could strain the sibling relation and affect the broader family dynamic. Such scenarios might prompt parents to reconsider their approach to family planning and genetic intervention, weighing the long-term emotional and practical implications for all their children.

Child's Future Ethical Perspective

Beyond the generational effects of genetic modification, personal identity also emerges as a significant area of concern. Growing up, developing a strong sense of self-identity is emotionally crucial, as it strengthens character and makes stronger individuals. If parents choose to disclose the use of CRISPR technology in their child’s genetic makeup, it could profoundly reshape the child's perception of their identity and who they were “meant” to be. Moveover, the use of genetic engineering to achieve specific attributes might create conflict within a child’s age, particularly when compared to peers of similar age. Feelings of guilt may also arise among individuals who benefit from such technologies, further complicating their self-concept. A critical perspective in these discussions comes from disability rights activists, who offer essential insights into the ethical regulation of a practice still poorly understood from a governmental standpoint. One proposed tool for addressing these ethical challenges is a decision tree- a framework designed to visually guide deliberation about the use of germline editing with CRISPR/Cas technology (Courtright-Lim, 2022). The decision tree provides a structured approach to ethical considerations and self-regulation from an activist’s point of view, emphasizing the need for thorough ethical scrutiny in advancing this technology. CRISPR also has broader societal implications that extend to how children perceive disabilities. This perspective could foster a societal view in which disabilities are seen solely as technological failures or burdens rather than aspects of human diversity. Such attitudes may lead to a loss of identity for those with disabilities, further alienating them from inclusive communities. This disconnect creates a troubling divide, where disabilities are perceived not as part of the human condition but as flaws to be eradicated.

Environmental and Economical

The long-term consequences of CRISPR technology remain uncertain due its early stages of development. When considering the effects of genetically modifying an organism, the focus often centers on the immediate implications for the individual. However, secondary effects- particularly economic factors- are equally significant and often overlooked. Currently, genetic engineering is in its infancy and accessible only to a select portion of the population. The projected costs far exceed the average family income, creating significant final barriers for many. For instance, exa-cel, a CRISPR-based treatment, is anticipated to surpass the already high pricing of Hemgenix- a non-CRISPR therapy estimated at $4 to $6 million for the lifetime treatment for severe spinocerebellar ataxia (SCA), a condition characterized by loss of muscle control and balance (Subica, 2023). In addition to exorbitant costs, disparities in medication pricing and limited access to CRISPR facilities could disproportionately marginalize minority communities. Systemic racism embedded in discriminatory insurance practices exacerbates this inequality, resulting in significant underrepresented minorities in gene-editing accessibility (Subica, 2023). As a result, these technologies are likely to remain available only to those of higher socioeconomic status, perpetuating a genetic divide that reinforces cycles of poverty and disadvantage. The global accessibility of CRISPR technologies presents another layer of inequality. While the United States leads advancements in gene editing, access to these innovations in low- and middle-income countries is severely restricted. This disparity not only widens the gap between wealthy and developing nations but also consolidates scientific power within the U.S., creating a monopoly that further marginalized those outside its sphere of influence.

Methodology

Study Design

This study determines (and to what extent) a person's opinion on editing embryos changes, based on the severity of a condition versus editing for physical preferences. The goal is to estimate how popular CRISPR (clustered regularly interspaced short palindromic repeats), a current clinical study, will be among the current generation and new generations that could bring in fresh offsprings. By uncovering these findings, scientists- such as microbiologists, inventors, and biochemists- can better understand the public's desires for the future of genetic editing, whether it is focused on physical traits or general health and wellbeing.

A quantitative phenomenological research study was conducted. Phenomenological studies focus on the philosophy of experience, recognizing that no two individuals have lived identical lives or viewed the world through the same lens. By narrowing down the choices available in such a study, researchers can better generalize public opinions about emerging technologies.

Phenomenology emphasizes consciousness and the content of conscious experience, such as judgments, perceptions, and emotions (Connelly, 2010). For this reason, a questionnaire was the instruction used for data collection. Survey questionnaires were more conducive for qualitative data compared to, interviews or open ended questionnaires because they provide an opportunity for wider perspective and capture a wider portion of the population's opinions.

Furthermore, other methods of study often assess the relationship between variables and their connections. Given the research question in this study, establishing one's morals regarding CRISPR technology can be linked to one's background or upbringing which can explain why demographic variables are asked prior to actual hypothetical questionnaire questions.

Participants

The sample consisted of majority high school aged students (N = 47, 66% female, 34% male) from ethnically/racially diverse high schools in a southeastern state. Participants varied from ages 14 to 66+. Among them, 74.5% ranged from ages 14-24, 12.8% ranged from ages 25-45, and the remaining 12.8% were evenly divided between 45-65 and 66+. Demographical data concerning ethnicities was heavily skewed as 35 (74.5%) were of White descent, 7 (14.9%) recorded Asian descent, and all other noted African American, American Indian/Alaska Native, Hispanic or mixed (all receiving one participant). Ideally, this sample will include students that will most likely have the availability to genetic engineering in their potential offspring. While this is the focus group, other subjects can consist of parents or individuals that have an interest in making this technology public or rather keeping it to clinical studies. A field of examination was whether or not children affected the opinions of genetic engineering in parents. To address this, question 5 asks if participants have/had children and data recorded represented a total of 8 (17%) participants recording having had children. Another piece of data that would have proved beneficial to this study, was if those that have been predisposed to genetic illness lean any specific way regarding CRISPR technology. While it would be optimal to narrow subjects to those that have had experience with exceptional ed, privacy concerns could arise. To avoid this, participants will be largely generalized to the public with an emphasis on high school students, parents, and facilities.

Procedure

Before the compilation of potential subjects could be collected, informed consent was gathered from administrators around southeastern United States schools via email. Originally, survey links were only going to be offered to a target population composed of exceptional education facility members that had previous experience with students in IEA-Individualized Education Account programs. This however posed a privacy concern regarding a FERPA Family Educational Rights and Privacy Act, to avoid such compilations, the survey was opened to the general public with an emphasis on high school students aged 14-19. A link to the questionnaire found on Google Forms was distributed through schools, which was then completed by students voluntarily during their free time. Participants were prompted to answer an online consent form (Appendix C) that ensured they were aware responses were to be kept confidential and demographic information (i.e., gender, age, race/ethnicity) would not be linked to specific identities.

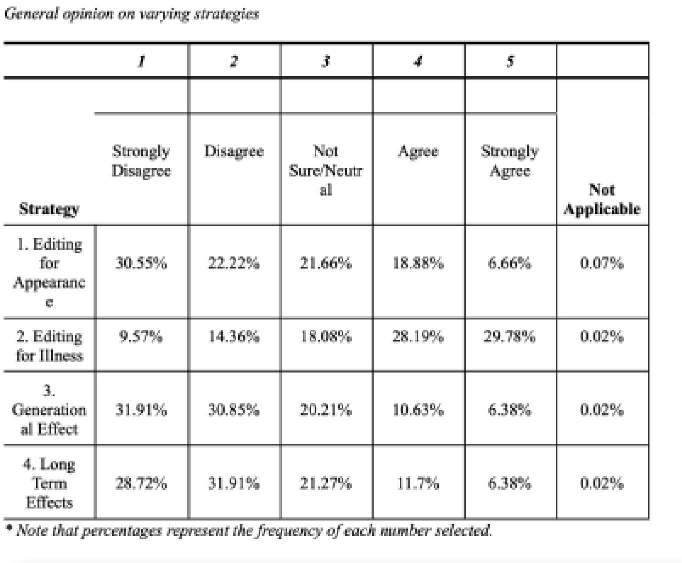
Materials

Participants were asked to fill out a questionnaire (Appendix A) using a five point scale to measure their attitudes regarding CRISPR technology. They were also asked general questions to gauge their demographics such as age, race, and gender; these questions used a drop-down menu and option to fill in an *Other* section. This survey consists of fifteen questions, some hypothetical and some opinion based. If questions were to bring up physiological trauma, participants can close the quiz at any time. In the case of internet connection uncertainty, the link or QR code the user used to initially open the quiz would continue to stay open until the data collection period comes to a close. Questions and data collection were approved by the IRB (Institutional Review Board) to ensure data collection would be appropriate to conduct.

Results

This study used a convenience sampling of the general public with a focus of highschool students. While this group matched the projected sample size with slightly over one-third of the overall age or a total of 35 individuals ages 12-24, other areas of information that were gathered were race, ethnicity and religious affiliations. Statistics concerning ethnicity didn't match expectations to be significant enough to measure accurate opinions. While it was assumed that close to an equal number of races would be recorded, slightly over one-third of responses were majority those of white background. A large majority of the findings regarding religious affiliation were also not up to the hypothesized number of responses, with less than three-thirds being non-religious.

The strategies seen in table 1 (Editing for Illness, Editing for Appearance, Generational Effect, etc.) have been grouped by a combination of questions that have been put together by subthemes. Questions such as "I would like to pick the genetic makeup of my child. (Hair color, height, intelligence)" and "I would take the chance of editing my child's physical appearance even if there was a risk of death." were some in the first strategy noted. Generally, the higher the number likert scale selected (1-5), the more positive the opinion is of that strategy. While opinions on each scale never exceed 32%, together likert values 1-2 and 4-5 combined did.



General opinion on varying strategies

	1	*2*	*3*	*4*	*5*	
Strategy	Strongly Disagree	Disagree	Not Sure/Neutral	Agree	Strongly Agree	**Not Applicable**
1. Editing for Appearance	30.55%	22.22%	21.66%	18.88%	6.66%	0.07%
2. Editing for Illness	9.57%	14.36%	18.08%	28.19%	29.78%	0.02%
3. Generational Effect	31.91%	30.85%	20.21%	10.63%	6.38%	0.02%
4. Long Term Effects	28.72%	31.91%	21.27%	11.7%	6.38%	0.02%

** Note that percentages represent the frequency of each number selected.*

TABLE 1. General opinion on varying strategies

As seen in the table, overall demographics did not have significant differences. There was a slight change in percentages when looking at the severity of the participants' choices. Strongly disagree and disagree were the ruled majority. Overall, with a focus group of the general population, most had a negative opinion of genetic engineering, with a total of 200.09% frequency. The total frequency for positive viewpoints was 118.6%, while 81.22% of choices were unsure or neutral. When taking into consideration the general population, it is important to remember some may have special experience in a specific topic or more knowledge than others. In the beginning of the survey, participants were prompted to answer questions such as, "I work with children that need special education to help acclimate to society." "And There has been a member in my family tree that has been affected by a disease." While the two questions don't necessarily mean an individual has specific specialized knowledge in CRISPR technology or genetic engineering, it may mean participants have been accustomed to the reality of living with a disability which could offer a new perspective.

Originally, age was hypothesized to affect the data that was collected greatly. However the outcome did not match what was hypothesized. Only one-third of participants were over the age of 25, which cannot be statistically measured to find a true distinction of opinion. Moreover, the goal in participants was to reach a highschool aged population to benefit the future of science; which can explain why there was a surplus in a younger aged population. Figure 1 as seen below, can represent the opinion of ages 14-24 and the frequency of each likert scale choice. Generally, the higher the percentage, the more that specific number was picked.

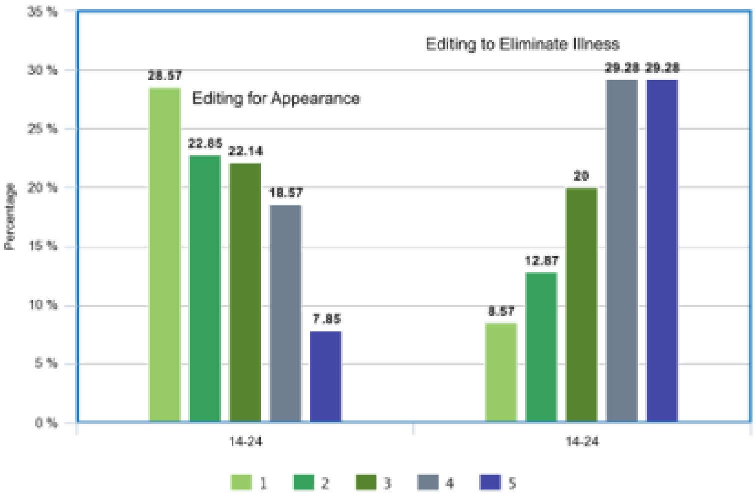


FIGURE 1. Opinions on Editing for Appearance vs. to eliminate an illness (focus group 14-24)

When eliminating all other age ranges and leaving ages 14-24, opinions of those that may have the availability of genetic engineering are displayed. Themes such as the generational effect and the long term effects seen in Table 1, have been omitted due to the lack of significance questions may hold. While topics “Editing for Appearance” and “Editing to eliminate an Illness” include four questions, omitted themes only include two. The goal of the study was to determine what the public thinks the purpose of genetic engineering should be. By examining the bar graph, it can be concluded that 58.56% of participants agree with editing for the purpose of relieving or eliminating an illness and of that percentage, 29.28 strongly agree. On the other hand, 51.42% (and of that, 28.57% strongly disagree) disagree with editing genes based on one's preference for specific physical attributes. The two themes nearly have completely opposite results which match the hypothesized results. One demographic that did not match the presumed data, was the female/male ratio.

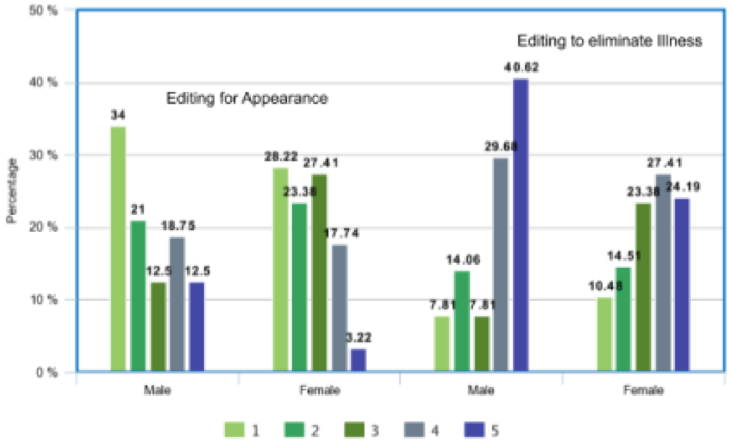
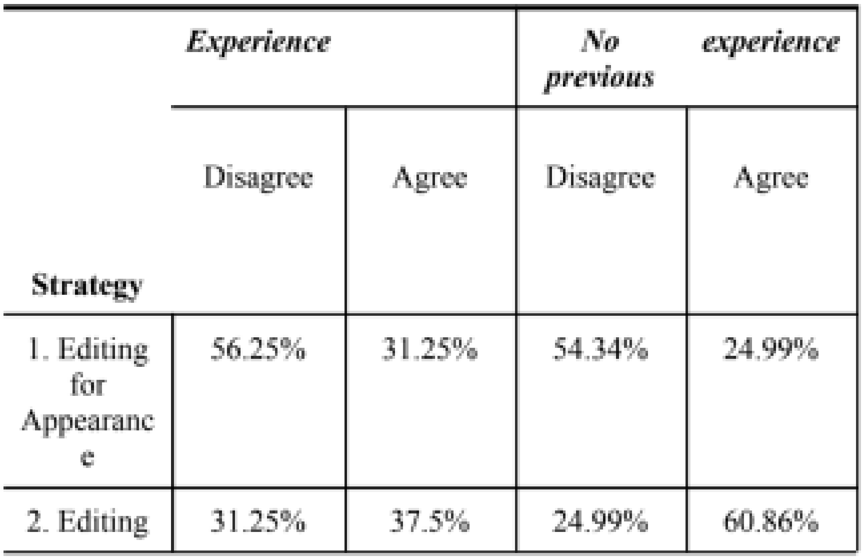


FIGURE 2. Opinions on Editing for Appearance vs. to eliminate an illness (focus group: Female vs. Male)

While considering the stereotypes surrounding the typical teenage girls priorities, one can assume that their main focus would be on physical appearance enhancements such as makeup or hair. This would mean a higher percentage of girls using CRISPR to achieve certain attributes. However, this ideology can be disproven by Figure 2. A total of 51.6% of females disagreed with editing for an appearance while 20.96% agreed that they would like to use CRISPR for physical enhancement. The hypothesized data for men in this figure matched what the research presumed, also matching the controversial stereotype that men are not as inclined to be motivated by their physical appearances. 55% of men disagreed with editing for appearance while 70.25% agreed with editing to eliminate illness (of that, 40.62% strongly agreed).

While assuming the majority of studied data came from those that had limited to no previous knowledge in the science, information collected concerning those that know a family member or friend that has been affected by a reversible illness. From the total sample size (N = 47) 4 participants documented both having worked with children that need specialized help and having known someone that has had a disability.

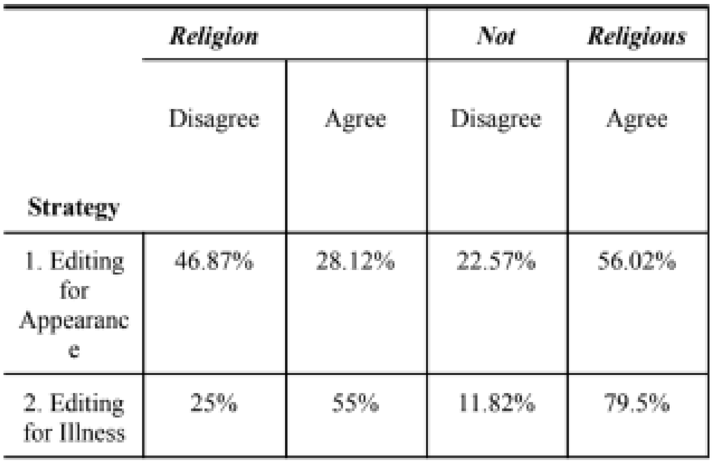
In the following tables (i.e. Table 2-3) are examples of generalized responses. In order to understand definitive opinions of the population, option choice 3 (I.e. Unsure/I don't know) was eliminated. Percentages seen is the frequency of choices picked on the likert scale. Answer choices 1 (Strongly Disagree) and 2 (Disagree) as well as 3 (Agree) and 4 (Strongly Agree) were combined to further generalize opinions and determine overall opinion.



Strategy	***Experience***		***No previous experience***	
	Disagree	Agree	Disagree	Agree
1. Editing for Appearance	56.25%	31.25%	54.34%	24.99%
2. Editing	31.25%	37.5%	24.99%	60.86%

TABLE 2. Opinions on Editing for Appearance vs. to eliminate an illness (focus group: previous experience with illness vs. none recorded)

Strong foundational source, *The Discussions Around Precision Genetic Engineering: Role of and Impact on Disabled People* by Gregor Wolberg sparked strong inspirational influence on the curiosity of whether or not experience of genetic engineering affected opinions. This was hypothesized due to the idea that certain experiences and predisposed life events might reframe someone's mindset. Wolberg was born without legs as a result of the prenatal drug thalidomide. His perspective after living life with a disability provided an interesting point of view many are not accustomed to. As seen in Table 2, the difference between those that have had experience and those who have not is only clearly apparent when looking at eliminating Illness. There was a difference of roughly 25% that viewed editing for illness in a positive light compared to negative. People without experience had more of a general positive experience in editing than those with experience. This could be explained using the idea of "therapeutic misconception" that was defined earlier in research. Those that don't have experience or as deep of an understanding in genetic illness might be quick to assume solutions. While assuming the majority of studied data came from those that had limited to no previous knowledge in the science, information collected concerning those that have had experience consisted of participants that know a family member or friend that has been affected by a reversible illness or have previously worked with special education students. From the total sample size (N = 47) 4 participants documented both having worked with children that need specialized help and having known someone that has a disability.



	Religion		***Not***	***Religious***
Strategy	Disagree	Agree	Disagree	Agree
1. Editing for Appearance	46.87%	28.12%	22.57%	56.02%
2. Editing for Illness	25%	55%	11.82%	79.5%

TABLE 3. Opinions on Editing for Appearance vs. to eliminate an illness (focus group: Religious vs. Non Religious)

Religion was the other main subject to study because it offers a variety of concerns and challenges many aspects of modern religion. As seen in Simo Vehmas research some theological thinkers believe that the value of a higher functioning succeed those that think there is meaning in suffering however this study contradicts that understanding as there was more of a positive outlook among non religious participants. The biggest difference seen here is the positive opinions of both religious and nonreligious in desired traits and illness elimination. There was a difference of about 28% in editing for desired traits between religious and non religious participants There was a difference of about 24% in editing to eliminate illness and religious between non religious participants

Discussion

The purpose of this study was to explore whether (and to what extent) the public's opinion shifts depending on the type of genetic engineering being considered. Prior to analysis, it was hypothesized that factors such as religious affiliation, age range, and personal experience with individuals with disabilities would produce the most significant differences in opinions. However, the findings largely challenge these initial assumptions. For instance, it was predicted that females would express more favorable opinions toward genetic editing for appearance, while males displayed a higher overall approval of editing for appearance alone. This surprising outcome could be influenced by various factors, including the rise of social movements and societal efforts to foster positive environments promoting female confidence. These developments may counter the narrative that increased social media use leads to a decline in female self-esteem. Additionally, while these factors provide plausible explanations, other influences- such as cultural shifts or individuals exposure to scientific advancements- might also play a role. Further analysis and additional data are necessary to explore these dynamics in greater detail.

Limitations

There were several limitations to this study that should be acknowledged. This study's sample size was significantly less than what was projected (N = 47). For this reason, a significant statistical representation of the public's opinion could not be measured. With this being considered, there also wasn't a diverse sample population, (74.5%) recorded being white. Other ethnicities consisted of "Asian, African American, American Indian/Alaska Native, Hispanic, and mixed". While there were a variety of backgrounds, it does not represent as diverse of a population as intended. Moreover, the initial purpose of this study was to measure opinions of those that have had specific experience or training with the care of exceptional education students. However this focus group was quickly dismissed in fear of possible FERPA (Family Educational Rights and Privacy) violations. Consequently, the focus groups were broadened to high school students. While teachers in CDC (comprehensive development classroom) couldn't be sought out deliberately, questions 7 and 8 were used to measure the participants' exposure to those that would have availability to genetic engineering. These questions read, "I work with children that need special education to help acclimate to society and there has been a member in my family tree that has been affected by a disease. (causing serious impairment of strength or ability to function)".

Implications

Regardless of limitations, this study lays the groundwork for understanding public opinion on a rapidly advancing technology. Exposure to technology like CRISPR is crucial to ensuring its capabilities are not misused. Educating those who may be unaware of the complex implications and moral issues surrounding genetic editing is one of the first steps in transitioning this clinical study into a widely accepted practice. The results of this study can help introduce the public to the concept, encouraging them to consider the possibilities of the new era in science and technology.

Given the nature of the study and the uncertainty surrounding the future of such a fast-paced technology, there are limited directions for immediate future research. One primary concern for scientists and engineers regarding CRISPR is ensuring that the technology is safe and accessible. Expanding research into factors that heavily depend on CRISPR, such as its application and ethical considerations, would provide valuable insights. Additionally, studies involving animal testing could offer useful perspectives. Currently, testing on animals like mice and rats is being used to approximate human biological reactions. While definitive conclusions cannot yet be drawn, CRISPR's applications in animal studies are also under investigation. Measuring public opinion on editing animal genes could also provide further insights for the science community. For this kind of investigation, researchers could ask similar questions to the same focus group, but with a focus on animal subjects rather than humans.

Conclusion

The purpose of this study was to explore whether (and to what extent) the public's opinion shifts depending on the type of genetic engineering being considered. The fast paced world of biomedical sciences is constantly evolving, yet there has been limited research addressing the specific question: What impacts an individual's opinion on genetic engineering? This research study aimed to bridge that gap and establish a foundation for future research in related fields. A variety of demographic factors and personal experiences were found to influence perceptions of CRISPR technology. However, the findings suggest that identifying one specific determining factor is far more complex than it may initially appear. This research provides valuable insights while highlighting the need for further exploration to fully understand the nuances of public opinion in this rapidly advancing area of science.

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Appendices Table of Contents

Appendices

Appendix A: Survey Questions

My age group is:
14-24 25-45 46-65 66 or older
Gender:
Male Female Other
My ethnicity is:
American Indian/Alaska Native African American/Black
Native Hawaiian/Pacific Islander Asian White Mixed Other
I have/had children
Yes No
I am religious
Yes No
I work with children that need special
education to help acclimate to society Yes No
There has been a member in my family tree that has been affected by a disease. (causing serious
impairment of strength or ability to function)
Yes No
I agree with the idea of designer babies, or a baby whose genetic makeup has been **selected** in order to ensure that a particular gene is present
Strongly Disagree Disagree Neutral Agree Strongly Agree
Not Sure I would like to pick the genetic makeup of my child. (Hair color, height, intelligence) Strongly Disagree Disagree Neutral Agree Strongly Agree Not Sure
I would take the chance of editing my child's physical appearance even if there was a risk of death.
Strongly Disagree Disagree Neutral Agree Strongly Agree Not Sure I would **not** like to know the long term effects of genetic engineering on my child. Strongly Disagree Disagree Neutral

Agree Strongly Agree Not Sure

If I were faced with a situation in which I was aware my child was going to be disabled with a disease such as Cerebral Palsy, a disorder that affects a person’s ability to move and maintain balance and posture, I would alter their genetic makeup to eliminate it.

Strongly Disagree Disagree Neutral Agree Strongly Agree Not Sure

If I knew the downsides of genetically editing my child that would affect the remainder of his/her life, such as chronic blood disease, or fertility issues I would continue the process.

Strongly Disagree Disagree Neutral Agree Strongly Agree Not Sure

If editing was successful, I would tell my child that they have been genetically modified to enhance physical appearance.

Strongly Disagree Disagree Neutral Agree Strongly Agree Not Sure

If editing was successful, I would tell my child that they have been genetically modified to eliminate an illness.

Strongly Disagree Disagree Neutral Agree Strongly Agree Not Sure

I would hope my parents would have genetically modified me if I had been projected to have a life changing illness.

Strongly Disagree Disagree Neutral Agree Strongly Agree Not Sure If I had been given the opportunity, I would have liked to have picked my physical attributes. Strongly Disagree Disagree Neutral Agree Strongly Agree Not Sure

I would sacrifice a large amount of my annual income to eliminate my offspring's genetic defect even if the unintended consequences were deadly or chronic.

Strongly Disagree Disagree Neutral Agree Strongly Agree Not Sure

I would still have a child if I knew he/she would be at a higher risk of being born without family genetic defects.

Strongly Disagree Disagree Neutral Agree Strongly Agree Not Sure

It would be fair for a healthy sibling to take full responsibility to take care of another chronically ill sibling after the parents have passed.

Strongly Disagree Disagree Neutral Agree Strongly Agree Not Sure

Appendices

Appendix B: *Blank Copy of Administrator Consent Form*

Note. Crossed out is the researcher's personally identifiable information. This was done to maintain anonymity.

Informed Consent to Participate in a Research

[redacted]

Title of Research Project: Possibilities of Designer Babies
Name of Principal Investigator: [redacted]
Phone Number of Principal Investigator: [redacted]

PURPOSE AND BACKGROUND: [redacted] from [redacted] College Board Advanced Placement Capstone Diploma Program is conducting research on the correlation between attitudes towards editing a debilitating disease out of an embryo and editing physical attributes into an embryo and the morals behind it. The purpose of your participation in this research is to help the researcher identify the public's opinions on genetic engineering. Your school, [redacted] [redacted], was selected as a possible participant in this study because of the high number of students and best chance of diverse subject count.

PROCEDURES: If you agree for [redacted] to participate in this research study, the following will occur: Participants will be prompted to answer a series of questions about their demographics, requesting information such as age, gender, race, ethnicity, and religion through a google form. Ensuring that they are aware all information will be kept confidential in a password protected chromebook. After the series of defining questions, participants will be given questions about their personal opinions in relation to genetic modification. Questions will be rated on a six-point Likert scale, where 0 = *Not Sure*, 1 = *Strongly Disagree*, 2 = *Disagree*, 3 = *No Opinion*, 4 = *Agree*, 5 = *Strongly Agree. T*his information will then be used to be converted into a percentage to determine attitudes of genetic modifications. Questions in such surveys will consist of hypothetical situations in hopes to avoid reliving personal trauma or experiences. Surveys should take no more than 10 mins of the participants time.

RISKS: The potential risks to the participants consist of fear of their data being released and that they could become overwhelmed while talking about their current or past experiences in relation to trauma or stress. Participants will complete and return consent forms previous to their participation in the study, however it is understood that the participants may be fearful of their exposed information. The participants' information will be guaranteed to be protected through a password protected chromebook. Participants will never be referenced in a way that can be identified and would only ever be identified using pseudonyms. Other risks may include being overwhelmed with more stress or negative emotions. If it becomes apparent that the participant needs assistance containing emotions they will be offered therapeutic facilities in their area.

CONFIDENTIALITY: The records from this study will be kept completely confidential. No individual identities will be used in any reports or publications resulting from the study. Research information will be kept in locked files at all times. Only the researcher will have access to the files and survey questions and no other will see names or other identifying information will have access to that particular file. After the study is completed all data and Informed Consent forms from the study will be provided to the instructor of record where they will be kept in a safe and secure location for seven years,then properly destroyed.

BENEFITS OF PARTICIPATION: There will be no direct benefit to you or [redacted] [redacted]from participating in this research study. The anticipated benefit of you and [redacted] [redacted] to participate in this study is the availability of genetic engineering to be offered to a wider variety of the population in the long run.

VOLUNTARY PARTICIPATION: Your decision whether or not to participate in this study is voluntary and will not affect your relationship with the [redacted]. If you choose to participate in this study, you can withdraw your consent and discontinue participation at any time without prejudice.

QUESTIONS: If you have any questions about the study, please contact[redacted] by emailing preferred email below. You can also contact [redacted] with any questions about the rights of research participants or research related concerns.

CONSENT

YOU ARE MAKING A DECISION WHETHER OR NOT [redacted] WILL PARTICIPATE IN A RESEARCH STUDY. YOUR SIGNATURE BELOW INDICATES THAT YOU HAVE DECIDED TO PARTICIPATE IN THE STUDY AFTER READING ALL OF THE INFORMATION ABOVE AND YOU UNDERSTAND THE INFORMATION IN THIS FORM, HAVE HAD ANY QUESTIONS ANSWERED AND HAVE RECEIVED A COPY OF THIS FORM FOR YOU TO KEEP.

Signature

____

____________________ Date __________________

Agency____

____

Research Participant Signature

____

_ Date __________________

Appendices

Appendix C: Individual Consent Form

[redacted] **of College Board Advanced Placement Capstone Diploma Program**

Title of the Study: Possibilities of Designer Babies

The general purpose of this research is to understand the relationship between attitudes of editing genes, based on the want of certain physical attributes, compared to the elimination of diseases. Participants in this study will be asked to answer a series of questions based on their opinions on different hypothetical situations surrounding genetic editing. Findings from this study will be organized statistically into an undergraduate-level research paper which will then be presented to a panel of their inquiry. From here, the findings may be published in a scholarly journal. (If you have any more questions about the AP Research program visit their website here.)

I understand that:

A. My participation in this study will take approximately 10 min max.

B. The probability and magnitude of harm/discomfort anticipated as a result of participating in this study are not greater than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations or tests. Participating in this research may result in feelings of anxiety or stress.

C. The potential benefits of this study include a possibility of having genetic engineering to become available to a wider variety of population in coming years.

D. I will not be compensated for participating in this study.

E. My participation is voluntary, and I may discontinue participation in the study at any time by closing the survey. My refusal to participate will not result in any penalty.

F. My responses will be recorded anonymously, and I cannot be identified by my responses.