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Bay Area Generation Z Opinions on Gene Editing

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ABSTRACT

Gene editing is known to be powerful, yet controversial. While it has the ability to significantly decrease human immunodeficiency virus (HIV) cases around the world, gene editing can also create an even greater socioeconomic gap. This academic discussion about gene editing has to address when gene editing treatments should be used as well as which type of gene editing treatments should be used. Currently there are two types of gene editing treatments, somatic and germline. Somatic gene editing treatments make modifications to DNA but do not affect reproductive cells. In contrast, germline gene editing practices do affect reproductive cells and modifications can be passed to future generations. The study aims to address San Francisco Bay Area Generation Z's opinions on gene editing (including which gene editing practices should be used).

To test the hypothesis that Generation Z will want gene editing treatments that are meant to treat diseases and other disorders, the researcher utilized a mixed methodology with an online survey. The results showed that somatic gene editing treatments for diseases and disorders in adults are the most preferred use of these technologies. By these means, legislation as well as other research should be done to promote access to treatments, such as those for sickle cell anemia, for the general public.

Introduction

The world of gene editing is constantly evolving and progressing. In 2014, researchers Jennifer Doudna and Emmanuelle Charpentier refined Clustered Regularly Short Interspaced Palindromic Repeats (CRISPR) practices and found new ways to accurately cut and replace DNA sequences (Doudna & Charpentier, 2014). In April 2022, scientists at Northwestern University further developed CRISPR technologies to create new long-lasting therapeutic strategies for Human Immunodeficiency Virus (HIV) (Hiatt, J, et al., 2022). Today, two types of gene editing practices exist: somatic gene editing and germline gene editing. Somatic gene editing refers to edits to the genome that do not affect an organism's reproductive cells. In contrast, germline gene editing affects reproductive cells and edited genetic material can be passed down to future generations. Most current research is focused on somatic gene editing because of the ethical concerns of germline gene editing. There are also two proposed uses for gene editing, therapy (treatment intended for relief or to treat a disorder) and enhancement (alteration to the human body in order to enhance physical or cognitive abilities). Many bioethicists have argued that gene editing should not be used to give enhancements, but rather just treat serious diseases (Fridovich-Keil, 2019).

While gene editing may offer wonderful technological advances, critics worry about ominous consequences. Some historians surmise that mass uses of gene editing will shift the human genome to favor certain physical traits and propagate eugenics (the selection of heritable characteristics to increase the occurrence of certain traits)(Agar, 2019). Others are concerned about unforeseen consequences. Many genes are pleiotropic, influencing two or more seemingly unrelated phenotypic traits, so altering one gene may have negative effects (Gratten & Visscher, 2016). Lastly, experts conjecture that gene editing treatments will be exclusively for the rich thus further increasing the socioeconomic gap in our society (Sharma et al., 2020).

Given such a controversial topic, it is important to investigate public opinions to make the best decisions for society. As explored later in the literature review, there have been countless studies on what the adult public believes about the uses of gene editing. However, the science community has not exclusively examined the younger generations, specifically Generation Z (those born between 1997-2012). It is important to consider what these individuals believe about gene editing because professionals estimate that within the next two decades, gene editing may be as common as cardiac pacemakers (Bleicher, 2020). Thus, Generation Z may be directly impacted by the presence of gene editing technologies. While gene editing therapies may not be as prevalent as the flu shot, when Generation Z starts to have children, gene editing techniques will be more readily available. Therefore, it is critical for individuals who may be directly affected or whose children will be affected by gene editing to have a say in the debate. Other studies have observed how public opinion varies in different geographic areas; however, the San Francisco Bay Area has not been exclusively studied. The Bay Area and Silicon Valley are hotspots for developing biotechnologies, including gene editing. Therefore, it would not be surprising to see individuals, including Generation Z, in this area being directly impacted by gene editing practices. This knowledge gap led to the following question: What do Generation Z individuals in the Bay Area believe about the uses of somatic and germline gene editing?

The researcher hypothesized that the studied population will be in favor of using both somatic and germline gene editing techniques for necessary medical concerns. The researcher hypothesized this because gene editing practices had initially stemmed from the desire to treat diseases and human enhancement (Fridovich-Keil, 2019).

Literature Review

In a study conducted by George Gaskell and several other researchers, over one thousand adults were polled from ten countries each. Participants were asked questions regarding their beliefs about gene editing. By asking questions that included gene editing both in prenatal and adult scenarios, the researchers were able to gauge the general consensus regarding gene editing. The results showed that treatments in adults were much more accepted than prenatal ones. In addition, females were more likely to be cautious about gene editing (Gaskell et al., 2017). Because the study included much larger geographic boundaries than this one and only focused on adults, it was not able to properly evaluate the opinions of Generation Z in the Bay Area. In addition, the education levels of the adults polled were not noted. As seen in Weisberg's study, the researchers noted that other factors can influence beliefs regarding gene editing. There are also a lot of arguments and situations that need to be settled in the gene editing community. For example, in her argumentative piece, Jennifer Gumer discusses how parents play an important role, but they could often wield too much power and make decisions that should not be made for children (Gumer, 2019). While a single research study cannot address all possible issues with gene editing in one survey, what is asked and not asked of participants should be noted.

Other organizations have conducted polls to evaluate the public opinions surrounding gene editing and its applications. For example in 2016, a survey conducted by Harvard and STAT collected data on the opinions of Americans on gene editing (both on adults and prenatal). Researchers found that while a large majority of Americans opposed prenatal gene editing, 44% of participants believed that federal funds should be used to support scientific research for prenatal gene editing for certain serious diseases such as Huntington's disease, cystic fibrosis, and types muscular dystrophies (STAT and Harvard TH Chan School of Public Health, 2016). Of all the participants, only 14% believed that the federal government should fund research on changing genes that could affect physical attributes, athletic ability, and intelligence. While a majority of participants did not express support for the government funding research for gene editing in embryos, 54% of participants who had knowledge on the current arguments supported funding for changing the genes of unborn children (STAT and Harvard TH Chan School of Public Health, 2016). Even though there is a great deal of opposition on other issues, a majority of Americans supported federal funding to scientific research on new gene therapies. While this study did focus on American opinion, its geographic boundaries were much larger than this study. However, this study did focus on how more research needs to be done in order for gene editing (especially germline) practices to make an appearance in a clinical setting. In her piece that demonstrated

insight on the Nuffield Council's decision, Katherine Drabiak describes how more research is necessary in order to pursue gene editing (Drabiak, 2020). Drabiak describes an opinion that may be highlighted in the feedback received from participants, and should be anticipated accordingly.

Another study conducted by Steven M. Weisberg and two other researchers from the University of Pennsylvania found that demographics had a significant impact on the opinions surrounding gene editing (Weisberg et al., 2017). In their study, the researchers polled a diverse group of Americans. They had over two thousand participants from all over the country, varying in attitudes and ethnicities. Adults from all ages and political views were included in this study, and all genders were also involved. While this study did not assess why different demographics affect support for gene editing therapies, it was evident that some individuals were more cautious than others. Like Gaskell's study, the researchers found that women were more likely to be "less optimistic about biotechnology than men." They were also more sensitive to potential risks and issues such as eugenics (Gaskell et al., 2017; Weisberg et al., 2017). Age also played a significant role in opinions. Younger participants were more open to genetic modifications and less likely to be adverse to the risks compared to their older counterparts. Other factors such as race, ethnicity, political views, and education levels were also noted to have an effect on responses. Even though these researchers mainly focused on opinions regarding gene modifications, they demonstrated that other demographic factors do need to be considered.

In 2020, Delhove et al. did a meta-analysis on several sources on public opinion on gene editing in humans (Delhove et al., 2020). They compiled 1,561 sources, and after screening source titles and sorting based on the researchers' criteria, 41 studies remained. Based on these studies, the researchers came to several key conclusions. They found that higher education and understanding of gene editing led to more acceptance of gene editing practices in humans. Similarly, to Weisberg and Gaskell's findings, they also found that men and women both seemed to be more opposed to germline gene editing over somatic gene editing in humans (Gaskell et al., 2017; Weisberg et al., 2017). Most of the studies examined in this research also found that men tended to be more accepting of gene editing than women. The range of risks associated with gene editing were also considered with 20 of the 41 sources in the meta-analysis considering the risks. These findings were similar to Weisberg's study that found women to be more hesitant to other new biotechnology practices. The study did not see any other differences when it came to analyzing other demographic factors (Weisberg et al., 2017).

Methodology

The aim of this research project was to answer the question, "what do Generation Z individuals in the Bay Area believe about the uses of somatic and germline gene editing?" The researcher conducted this study according to the methods approved by the Institutional Review Board at their high school. All participants provided informed consent (Appendix A).

Methodology Choices

This study used a descriptive research method with a survey. A descriptive research design was found to be the most appropriate to describe the trends and phenomenon in a population (Nassaji, 2015). In addition, the debate regarding gene editing is not a black and white situation simply answered with "I agree/disagree". This method design allows the researcher to evaluate the reasoning behind participant's decisions to gain a better understanding of their beliefs (Nassaji, 2015). A study by Havard STAT in 2016 polled about two thousand Americans on gene editing and its uses and found a correlation between various factors such as race and gender and the acceptability of uses (STAT Harvard T.H. Chan School of Public Health, 2016). Therefore, there were questions (e.g. race, ethnicity, religion, etc) included in the survey that allowed for the researcher to consider if and which factors showed similar correlations in a younger population and in the Bay Area specifically.

A case study was not used because the researcher wanted to evaluate the Bay Area beliefs, and they wanted to consider a large population of people. They also believed it was an inappropriate method because the researcher wanted many other demographics to be considered in this project. In a similar manner, interviews were not chosen because of its lack of feasibility and ability to cover many different individuals and their views.

A qualitative and semi-quantitative approach was also utilized to understand participant views as much as possible. In the questions directly about gene editing, participants were asked to read different scenarios then rate how much they agree or disagree on a scale as well as explain their answer. The average numbers allowed the researcher to quantify the agreeableness levels while the qualitative data provided an understanding of the reasoning.

Survey Choices

The survey was adapted from Gaskell's 2017 study on public views on gene editing (Gaskell et al., 2017) in which participants were given four different scenarios and asked how much they agree or disagree with the scenario. For this study, the survey had three main components: an introduction section, a demographic questionnaire, and gene editing scenarios. See Appendix B for the full survey. For the introduction section, participants were asked to record their initial thoughts and knowledge about gene editing. They were then asked to read a couple of paragraphs on what somatic and germline gene editing are as well as some current arguments so they could be properly informed of the existing knowledge and debate. After the reading, the same two questions before the paragraph were asked again to see if there was a change or trend in beliefs about uses of gene editing. Next, individuals were asked to complete a demographic questionnaire asking about race, ethnicity, religion, education levels, gender, and sexuality. Weisberg et al., Delhove et al., and Harvard found that different demographic groups may respond differently to certain gene editing practices (STAT and Harvard TH Chan School of Public Health, 2016; Delhove et al., 2020; Weisberg et al., 2017). Therefore, the researcher felt it was fitting to consider demographic factors to see if there were similar results. The final component of the survey contained four different gene editing scenarios in which participants indicated their approval levels and explained their decisions. In this study, the researcher utilized four scenarios similar to Gaskell et al., 2017. These scenarios included using gene editing for adult therapy (treating sickle cell anemia), prenatal therapy (preventing dementia), adult enhancement (increasing cognitive abilities), and prenatal enhancement (increasing intelligence quotient score [IQ]). Unique to this study, the researcher included a ten-point scale to rate how much the participants agreed with the scenarios as well as a short answer section where participants could explain their opinions or logic. A 1 to 10 scale was used with 1 being complete disapproval and 10 being complete approval. A ten point scale was chosen because it was anticipated that most participants would have knowledge on the topic; therefore, the scale could offer a higher degree of measurement precision (Coelho & Esteves, 2007). In addition, there were only four questions with scale components, so the researcher anticipated that there would be minimum fatigue from ten point scales. At the end of this section, there were two final questions about final thoughts as to whether they felt they experienced any change in views after participating in the study.

Survey Distribution

The researcher distributed a Google form questionnaire at a Bay Area high school. At the researcher's high school, a link was shared to trusted school faculty to share with their students. A QR code of the Google form was also available to make distribution easier on campus. To reach individuals outside of the high school, the researcher integrated snowball sampling to email individuals outside of this Bay Area high school and texted the link to the online survey. Data was collected and stored in a secure Google Drive file. No personal identifying information was collected. If individuals wished to follow the results of the survey, they could provide an email address; however, no data was linked to this email address.

Analysis

The researcher inputted the responses collected onto a Google Sheet For the quantitative components of the four scenario questions, average scores were calculated and compared to determine if there were any major differences among the different scenarios. For the qualitative questions, all written responses posted into the Google Sheet Responses were color coded based on being positive, negative, or neutral. Once all responses were color coded, the researcher examined the various responses for trends in reasoning and logic behind responses. Responses that contained popular components such as disagreeing with practices due to detrimental consequences were noted. Demographic data was then factored into the data analysis. The researcher looked for trends between different groups and their opinions on gene editing. Finally, all of the components (including the demographic data) were factored into the data analysis to determine if there was a difference between the different variables and responses. The researcher examined the collected information for further trends and made several observations listed in the analysis section.

Results

Survey

The survey yielded 134 responses. The researcher removed one response due to incoherent responses. The final sample size was 133. In review of the data, the researcher noted some categories consisted of only one to five participants and were thus grouped into "other."

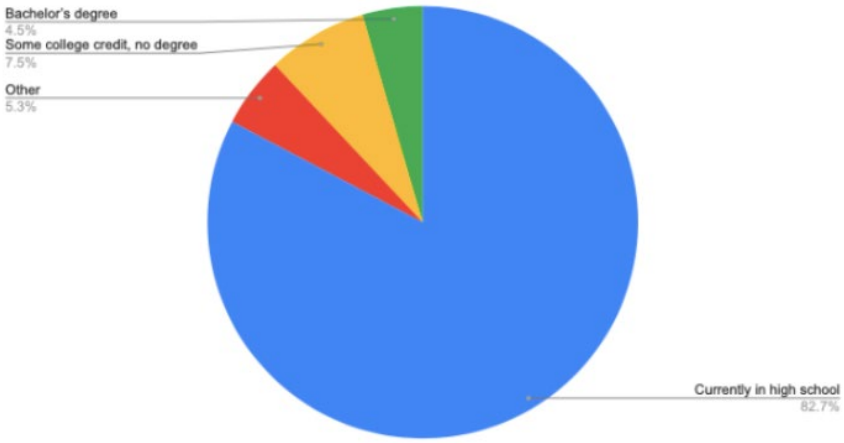

Figure 1. Count of "Which of the following describes your educational background? Choose the highest level that applies to you."

With regards to educational background, the majority of the participants were high school students (82.7%). See Figure 1. The second largest group had college credit but no degree. The remainder of participants included individuals with some high school credits, high school diplomas or equivalents, bachelor's degrees, and other forms of training.

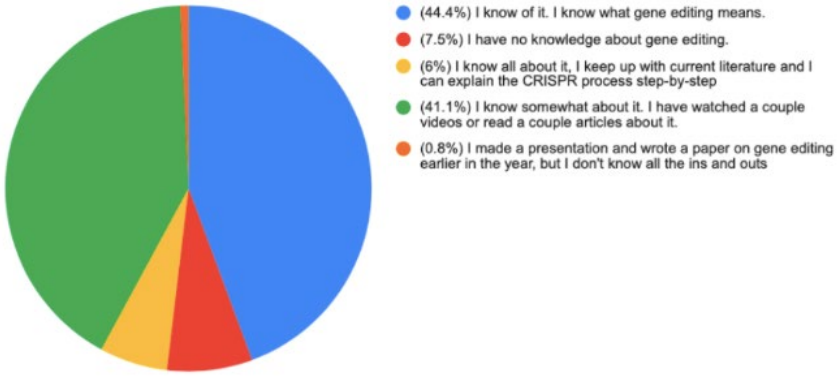

Figure 2. Count of "What is your current understanding of gene editing?"

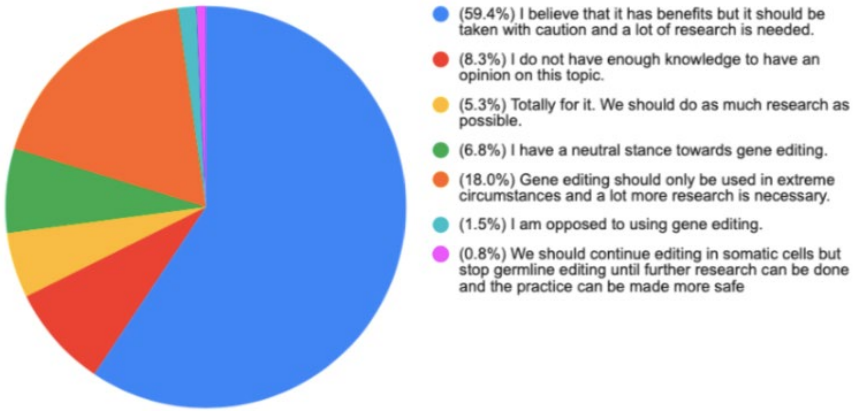

Figure 3. Count of "What are your current beliefs regarding gene editing?"

Figures 2 and 3 describe the participant's understanding and beliefs respectively about gene editing. With regards to understanding, 44.4% of participants had at least some understanding of what gene editing was. See Figure 2. Six percent of participants stated that they keep up with the current literature and are well versed in the CRISPR processes. Fifty-nine point four percent of participants stated that they believe gene editing provides a lot of benefits, but practices should be taken with caution See Figure 3. A small 5.3% believed that as much research as possible should be done, but an even smaller 1.5% were opposed to gene editing uses.

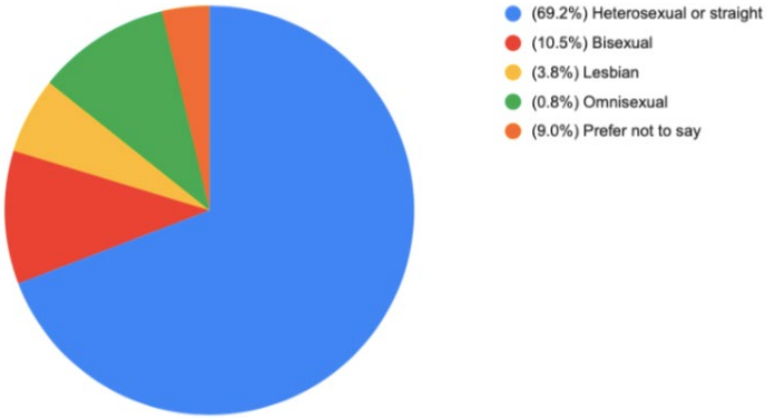

Figure 4. Count of "Which of the following sexual orientations best describe you? Select the most applicable to you."

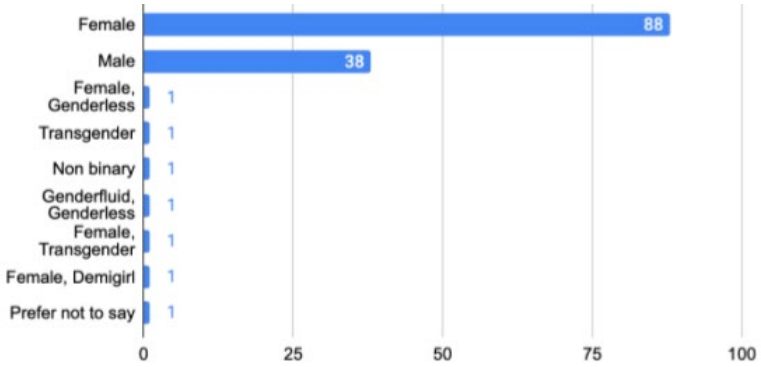

Figure 5. Count of "Which of the following genders do you identify as?"

Figures 4 and 5 show the participants' sexual orientation and genders respectively. Sixty-nine point two percent of participants identified as heterosexual/straight. Other common responses included: gay, bisexual, and asexual. Ninety-one participants identified as female; 38 participants identified as male. See Figure 4. With regards to gender identification, there were five main groups. See Figure 5. The largest group identified as heterosexual/straight.

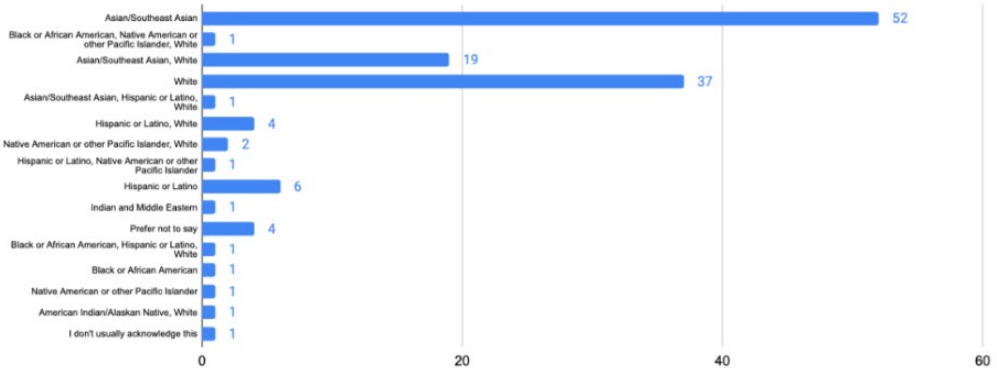

Figure 6. Count of "Which of the following races do you identify with?"

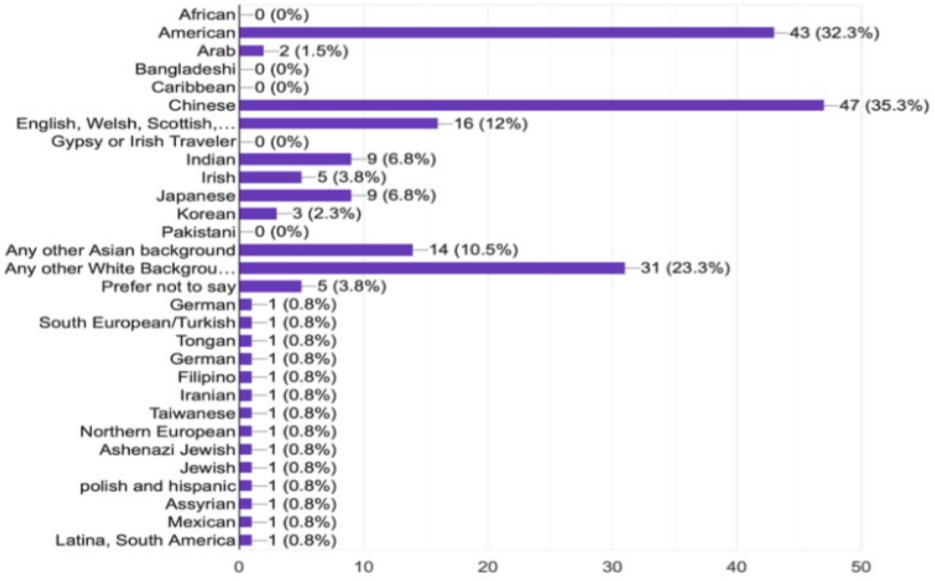

Figure 7. Count of "Which of the following ethnicities do you identify with?"

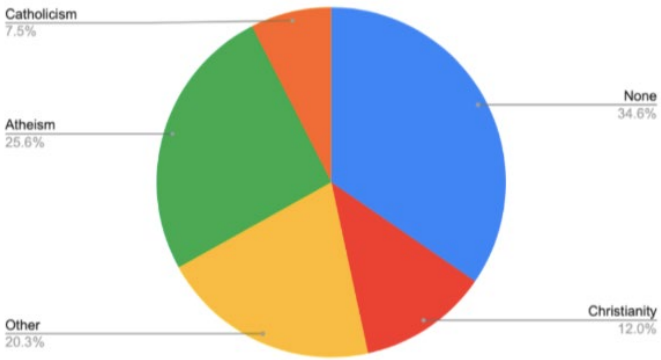

Figure 8. Count of "Which of the following religions applies to you?"

Out of the 9 reported races, the two biggest populations were Chinese and White with 72 and 66 participants in their respective categories. See Figure 6. A total of 25 different ethnicities were included in this study. See Figure 7. The largest groups included Chinese, American, and Any Other White Background. A majority of participants indicated having no religion or following Atheism. See Figure 8. However, for the remaining participants, there was a large mix of religious backgrounds, ranging from Christianity and Catholicism to Hinduism and Greek Orthodoxy. The main religious groups were Christianity, Catholicism, none, Atheism, and others. This grouping was done because some groups did not have enough people.

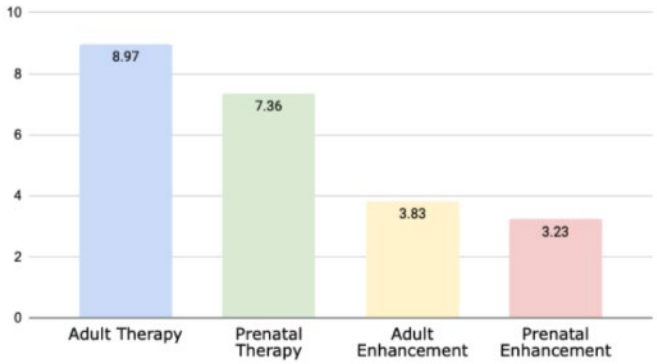

Figure 9. Average Scores for Gene Editing Scenarios

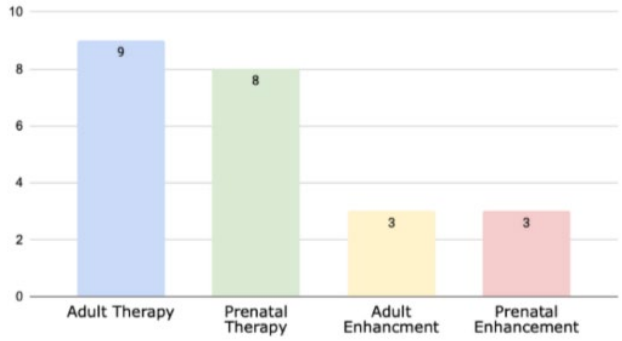

Figure 10. Median Scores for Gene Editing Scenarios

Figure 9 and Figure 10 show the numerical averages and medians of the population respectively. Adult Therapy was given the highest average score with an 8.97, and Prenatal Enhancement with a score of 3.23. There is a very small difference between adult enhancement and prenatal enhancement and these observations will be followed-up in the limitations. The researcher also included the median scores to understand where the midpoint of answers were. The median values were also considered in case the averages provided an inaccurate representation with skewed data. About half of the survey was used to collect qualitative data. Participants were allowed to justify and further explain their responses. In the explanation section, participants showed high approval of adult therapy. Many explained that the treatment was necessary, did not give the individual an advantage, and the individual could make their own decisions. Prenatal therapy was the second most approved category. Some respondents were concerned about the risks of germline gene editing and the parents exerting too much control; however, many focused on the benefits of the treatments and felt it was necessary. Both adult enhancement and prenatal enhancement received unfavorable responses. Many argued that the treatments were unnecessary and not worth the risks.

At the end of the survey, respondents were asked if their opinions on gene editing had changed. One hundred-three of the respondents claimed that the survey had not changed their opinions. Seventy-two participants even claimed that the survey solidified their beliefs.

Women were also found to be more cautious of gene editing than men. They tended to focus more on the social and ethical ramifications in their responses. One female participant stated, “I am all for their child not suffering from dementia when they get older, but they do not know about other side effects that could arise later in their child's life.” Many other female participants had a similar cautious tone in their responses. In addition, those with a greater understanding of gene editing tended to be more supportive of the gene therapies (not necessarily enhancement treatments)

than those with less knowledge. While they did consider the risks, they tended to focus more on the benefits of the treatments. This group also used more direct language (e.g, should, wrong) in their explanations compared to other participants in the study. There were no other major trends noticed among the other demographic categories.

Discussion

The study investigated what Generation Z in the Bay Area believed about gene editing's uses. Overall, participants were in favor of using some forms of gene editing. They mostly agreed with types of gene editing that can be used for medical reasons and help people who really need it. Participants also were more accepting of somatic gene editing practices. Many explained that they are more accepting of somatic gene editing because it did not affect future lineages and if any unintentional edits do occur then it would not impact future generations. This study's findings were similar to Weisberg's which argued that younger adults were more accepting of gene editing than older adults.

As hypothesized, adult therapy was the most acceptable gene editing practice. Many participants commented that the practices would increase health and quality of life. Another reason participants approved of adult therapy is that the patient may not be able to live without the treatment. Many participants felt that the risks are worth the reward. Others noted how since the treatment was a somatic gene editing practice (and if there were any editing mistakes), the changes would not be passed down to future generations. There were some participants who were concerned about the side effects, but most argued that sickle cell anemia is a painful disease that should be treated. One of the most important decision factors was the power to choose. Many participants reasoned that the adult therapy was more acceptable because the adult patients could make their own choices. This is a very similar result to Delhove et al. 's work where participants were accepting of gene editing in adults because of the adult autonomy (Delhove, et al., 2020).

Contrary to the hypothesis, prenatal therapy does not have the same approval ratings as adult therapy. While many participants were in favor of this treatment, others worried about the possible risks. A number of participants were concerned that germline treatment mistakes could be passed down to future generations. Even though there are less 10s for this type of treatment, it was still much more popular than the enhancement treatment scenarios. Most of the participants agreed that the treatment would not create cognitive advantages for the child and would lessen future pain.

Participants were least approving of the prenatal enhancement treatments. This scenario has the most number of 1s with 37 participants giving this rating. Many argued that edits similar to this one could create unfair advantages for those who could afford this treatment. Others added that the treatment comes with a lot of risks and could be a "slippery slope" meaning that there could be a lot of side effects. Most participants believed that the risks did not outweigh the benefits and that the treatment is unethical and superficial. These identified trends among Bay Area Generation Z individuals were congruent with other academics who asserted gene editing takes away a child's autonomy and gives the rich an advanced genome, but that germline gene editing risks outweigh the benefits (Gumer, 2019).

Adult enhancement was also frowned upon. Many claimed that it is unnecessary, unethical, unfair, and the wealthy can get an unfair advantage. Literature has also shown that people in general have been generally opposed to enhancement (Delhove et al., 2020). Excessive uses of gene enhancement was hypothesized to create unfair advantages for the wealthy and can ruin some parts of the human genome. Other studies have argued that the human genome is meant to evolve naturally, and that mass use of gene editing can disrupt naturally occurring patterns and create unforeseen consequences.

Men tend to be more approving of gene editing practices than women. Throughout the responses, women tend to consider the risks more than the rewards of each treatment. Women also examined the ethicality and social impact more than men. These findings are similar to the results in Delhove's study which found that women over the age of 18 were less likely to approve gene editing than men over the age of 18 (Delhove et al., 2020). While many participants of this study were not over the age of 18, it follows a similar trend of men being more approving than women.

Participants with more knowledge about gene editing were more approving of gene editing therapies than those who have a basic understanding of it. These findings also align with Delhove et al., which found that those with more knowledge about gene editing tended to be more accepting of gene editing practices. The individuals in this study acknowledged the risks and possible negative implications of gene editing; however, they tended to focus their answers more on the positives rather than the negatives. In general, these people gave more 1s and 10s or stronger answers (in comparison to those with less knowledge about gene editing). This could be because they felt more confident in their knowledge or that their level of understanding led or that their level of understanding led to a more confident answer.

Finally, when comparing the other demographics, there are not many differences between the different categories. These categories included race, ethnicity, sexuality, religion, and education level. These categories are also further discussed in the limitations.

Conclusion

Ultimately, Generation Z Bay Area individuals show approval of adult somatic gene-editing therapies, or treatments for medical needs. There is also a general consensus that gene editing practices should not be used for enhancement, especially if it could give individuals unfair advantages and widen the socioeconomic gap. Somatic gene editing practices were also favored over germline gene editing practices. A majority of participants agreed that somatic gene editing practices are safer than germline gene editing practices because there is not the risk of passing edits to future generations.

Limitations

While the researcher provides valuable information to this field, it is important to consider the limitations of the study. First, the researcher chose a survey instead of an interview. Because of this choice, the researcher was unable to ask follow-up questions to the participants. If clarification was needed, the researcher merely inferred what the participants meant to the best of their ability. The second limitation is that some demographic groups did not have enough respondents. Eighty-two point seven percent and 72 out of 133 respondents identify as being Asian/Southeast Asian and in high school respectively. Some races and ethnicities have only one or two individuals, and there are several sexual orientations and genders that had less than ten individuals. If there have been more individuals in certain groups, or if the researcher had asked questions directly relating demographic characteristics to gene editing opinions, a relationship between demographic factors (besides gender and understanding of gene editing) could be established. Next, while the researcher chose method procedures that they thought would best fit the research question, there were still limitations. For one, to decrease participant burden, the researcher limited the amount of survey questions. Questions that captured more in-depth reasoning and identified sources of participant background knowledge were excluded so that the survey could be completed in a ten-minute window. Lastly, the 1-10 scale used in the survey was far too large for this study. Respondents who give similar numerical answers (e.g., 8 and 9) give similar explanations to their responses. While it is clear that the adult therapy is still the most approved of option, having a smaller scale, such as a 1-5 scale, may provide a clearer picture (especially in distinguishing quantitatively between adult and prenatal enhancement) about gene editing opinions.

Implications

The research indicates that Generation Z Bay Area individuals are supportive of gene editing therapies that are used to treat medical needs. The data suggests that even though there are some concerns about the risks and negative consequences, many people support gene editing medical procedures, especially if there are no other effective treatments.

Other research should be done to determine when the gene editing treatments should be used over other existing treatments. It is important to consider when non-gene editing treatments may be better for patients and certain situations. This type of research will also increase the public's understanding about gene editing practices so that they can further contribute to academic conversation (Gaskell et al., 2017). Since the data shows strong support for adult gene editing, it would not be surprising to see more legislation that allows people who have diseases such as sickle cell anemia, to get better access to gene editing treatments.

Since those with a greater understanding of gene editing showed strong opinions about its uses, society should consider developing more opportunities for the general public to discuss and learn about gene editing. This discussion should not be exclusive to researchers and medical professionals, but rather inclusive of the general public. A multidisciplinary ethical board is necessary to address not only medical advances, but the social and economic factors of gene editing.

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