Final Qualitative Research Project

Social and Ethical Impacts on Geneticists and Gene Editing Research

As a biology major, I have always been interested in the particular field of genetics, and the technology and research that results from it. This is why I decided to focus on gene editing technology, specifically clustered regularly interspaced short palindromic repeats and CRISPR-associated protein 9 (CRISPR/Cas9) for this project. This is a tool that was adapted from bacterial immune defense system, which allows scientists to directly edit DNA by adding, removing, or altering DNA sequences, offering advantageous uses in medicine to treat diseases. In addition, throughout my STEM classes in both high school and college, I have always gravitated toward understanding the genetic aspect of scientific processes from trait inheritance to genetic applications in medicine. I also had the opportunity to further explore this inclination in my genetics class, where I read and learned in further detail genetic processes like mitosis and meiosis, mutations, genetic testing, and more. When I would look over my notes and study for exams, I would enjoy doing so and not find it to be something extremely difficult for me to do. In addition, when conducting lab experiments and subsequently writing corresponding lab reports, I would diligently work for hours, finding it interesting and enjoyable putting the pieces of the experiment together and developing conclusions. I would feel extremely proud and satisfied with my final lab report, knowing that it was not just completed because it was an

assignment, but because I also enjoyed writing it. Furthermore, as this is a subtopic of biology I really enjoy, as well as a field I intend to pursue for my career, I found it to be an intriguing topic to write about for this project. Specifically, gene editing has become of interest to geneticists, leading to research for the exploration of the technology that could prove to have beneficial effects on clinical uses.

Within the genetics field, an issue that has shifted to the forefront in recent years is the ethical concerns surrounding from the recent development of gene/genomic editing technology. The advancement of this technology, CRISPR/Cas9, has made gene editing a more common reality, posing a question whether it is a tool that is ethical to use in medical practices. The technology is very lucrative in treating genetic diseases that have gone without useful or successful treatment for years, like sickle cell anemia and genetic disorders that are similar. However, CRISPR/Cas9 is not the first gene editing tool; its predecessors such as meganucleases, zinc finger nucleases, and transcription activator-like effector nucleases also gave scientists the opportunity to edit genes, but they were not nearly as precise, practical, accurate, and as sophisticated as CRISPR/Cas9 has proven to be. This technology allows scientists and doctors to specifically target malfunctioning genes, either by correcting the error in the genome, introducing new sequences within the genome, or turning on/off expression for certain genes. However, many individuals, both from the scientific community and outside of it, present concerns on whether the technology should

or should not be used since it can open the door to artificially selecting genetic traits in embryos and could go without regulation. That is, where can the line on the use of this technology be drawn? Although the technology proves to be useful in treating various genetic diseases, CRISPR/Cas9 can be exploited by inserting/removing any genes both working and not working at the whim of anyone, particularly for the selection within embryos, creating life and playing God. This is why many scientists are now calling for the possibility of placing limitations on the applications for which the technology can be used, because if the technology is not understood, it can easily be misused. Understanding these ethical issues, it presents a dilemma for genetic researchers and their studies. That is, if ethical concerns stand in the way of this research, there is a possibility of it impeding and leading to further implications on the technology and future advancement of the research and geneticists in general. Many geneticists are unsure how to proceed with their research, if both related and not related to CRISPR/Cas9, because of the ethical concerns presented by the public.

The ethical issues raise questions on geneticists' ability to continue their research and may affect the way in which they choose to proceed in the future for this technology as well as genetic research overall. Scientists are emphasizing this predicament; they are concerned if they should even choose to continue their research or abandon it completely. Consequently, geneticists' feel that their research is at a standstill because they do not know how to proceed without setting off alarms on ethical ideals and are concerned that their continuation of

the research will lead the way for misuse of the technology. Geneticists are emphasizing that disclaimers and limitations must be placed on the research prior to making it publicly available. Overall, the aim of this study is to recognize the implications that these ethical concerns have on geneticists and their research. Some unanswered research questions for this topic include: how does the framing of geneticists' research on gene editing impact the public perception of the technology; what implications does this perception have on geneticists and their research overall; how do these implications affect further advancement of the gene editing technology; and how does the public's perception of gene editing influence geneticists' research and approaches in the field? However, an overarching research hypothesis is that the public's perception of gene editing technologies, specifically CRISPR-Cas9, influences researchers and approaches in the field to tailor how they explain and distribute their studies to be more inclusive to those outside of the scientific community, enabling the research to be interpreted more accurately.

Methodology:

This paper presents a qualitative analysis on the ethical issues that geneticists and scientists are facing with the rise and development of more sophisticated gene editing technology, particularly regarding the CRISPR/Cas9 tool. Interviews were conducted using pre-selected questions with various scientists working at Pace University. A somewhat structured set-up was used for conducting the interviews in order to collect initial data from a scientific point-of-view, while leaving an

opening for outside research to be conducted based on current conversations presented in papers within the genetics field. In addition, the interviews left the opportunity for the interviewees to discuss anything regarding the topic at hand that they felt was important to mention and emphasize during the conversation. The names and educational backgrounds of each interviewee is important as it influences their opinion on the topic as well as their understanding. My first interviewee is Dr. Aaron Steiner, a genetics professor at Pace University who also conducts his own genetics research on tissue regeneration. My second interviewee is Dr. Tim Myers, another professor at Pace University specializing in neurobiology also conducting his own research. My third interviewee is Dr. Kimberly Stephens, also a professor at Pace University. These professors offer unique scientific perspectives and expertise about this technology and can speak from an analytical point of view regarding the challenges scientists face with CRISPR-Cas9 technology and others that are similar. Each of these professors were asked the same series of specific questions concerning CRISPR/Cas9 and its ethics. The questions are as following:

1. Currently, how are geneticists' research on the CRISPR/Cas9 technology presented in papers?
2. How could geneticists' present their research in order to better clarify to the public what it is exactly about?
3. What are the kinds of ethical issues that arise as a result of this technology and are there any ways that these ethical issues can be remediated?

4. How could these ethical issues and public opinion affect advancement of this technology and others that are similar?
5. How can these opposing views impact clinical uses of the technology?
6. How could this perception impact the development of further genetic research? Are there alternate methods to continue this research if obstacles are encountered, like ethical opinions?

The interviews are to be conducted in person and/or via an online video-chatting platform, like Zoom, depending on availability of both interviewer and interviewee. The interviews will be completed in an orderly fashion, asking the pre-determined questions in order while leaving the opportunity for the natural course of the conversation to proceed. The interviews took about 10-20 minutes long, depending on the contributions of the interviewees in terms of their inclusions of more or less information within their answers.

Literature Review:

Introduction

The two themes noticed throughout the current literature regarding CRISPR-Cas9 and genome editing technology are the public opinion on ethical considerations and the influence of public perception on geneticists' research. Each of these themes provide a different aspect that geneticists are facing with the rise and development of more modern and sophisticated genome editing technology, specifically CRISPR-Cas9. In particular, these themes allow readers to better understand the explicit ethical issues that the public presents with the use

of CRISPR-Cas9 and gain a perspective on the possible limitations that may need to be placed on the technology as well as the implications these ethical positions have on the future of genetic technology.

Public Opinion on Ethical Considerations

One such article that shares this theme is entitled “CRISPR Ethics: Moral Considerations for Applications of a Powerful Tool” and is written by Carolyn Brokowski and Adli Mazhar. This article discusses the present ethical issues that exist and surround the current scope of genome editing technology, specifically referencing the most advanced and sophisticated type, CRISPR-Cas9. The specific ethical concerns analyzed within the article are the extent to which CRISPR-Cas9 use should be permitted, access to CRISPR-Cas9 technology, whether regulatory systems for clinical research may accommodate gene editing technology, and whether international regulations governing CRISPR-Cas9 use should be created. However, this article also characterizes the possible interventions that can be implemented within the field to provide strict and limited uses of the technology. That is, the article first lays out the technology itself and its applications, then how the complex technology affects ethics, and lastly, presents and assesses a list of key ethical considerations. The authors conclude that moral decision making should evolve as findings in genetic engineering advance and also emphasize that there may be a benefit in application of governing bodies/legislation to prevent misuse of the technology. This article describes various ethical concerns that are present regarding the use and further advancement of this technology, which

provides more specific insight on the exact issues that are being faced. Additionally, this article allows readers to better understand the complex concerns that surround CRISPR-Cas9 and its implementation in the field of genetics.

Additionally, the article entitled “CRISPR-Cas9: A History of Its Discovery and Ethical Considerations of Its Use in Genome Editing”, written by Irina Gostimskaya, also shares this theme. This article provides detailed information regarding the development of the CRISPR-Cas9 technology and its current uses within the field. The author highlights in particular the advantages to using CRISPR-Cas9 as opposed to older methods; due to its unique characteristics, it presents the potential to revolutionize medicine. This article also includes the calls for ethical concerns/considerations not only from the public forum, but also from within the scientific field. That is, it details the issues and thoughts from scientific experts on how the technology could be misused and presents their apprehensions regarding safety and access, since the technology can directly affect the germline. This article also may add further specific information about the technology itself and provides insight into the thoughts scientists have regarding the technology and does not just shed light on the public perspective.

Equally important, the article entitled “Science and Bioethics of CRISPR-Cas9 Gene Editing: An Analysis Towards Separating Facts and Fiction”, written by Adam P. Cribbs and Sumeth M. W. Perera, discusses this theme further in detail. This article characterizes more ethical concerns surrounding CRISPR-Cas9, especially based on the fact that the technology is much faster and cheaper than

other previous existing techniques, making it more desirable. Such ethical concerns examined include unintended alterations within the genome and the potential misuse leading into the possibility of upholding eugenics. The article also includes that these ethical concerns may have an influence on the technology itself and its possible uses in the clinical setting. Another important aspect of this article is that it provides a historical perspective on gene editing technology and how that fits within the modern technique of CRISPR-Cas9. It references other past technologies used for gene editing in the past, including zinc finger nucleases (ZFNs) and transcription activator-like effector nucleases (TALENs) and how CRISPR-Cas9 offers novel applications in medicine. Also, it provides insight into the legal issues present globally, particularly referencing the WHO, UNESCO, and Declaration on the Human Genome and Human Rights. This feature may display the impact that the ethical concerns have on its future uses, seeing as there are legal roadblocks that exist.

Influence of Public Perception on Geneticists' Research

Although there is much discussion regarding the ethical concerns that surround CRISPR-Cas9 technology, it is difficult to find research that examines the influence that these public opinions have on geneticists themselves and their research. However, one such article that discusses this is entitled "Genome Editing: Past, Present, and Future" and is written by Dana Carroll. This article details the issues that surround current gene editing technology, specifically highlighting CRISPR-Cas9. However, this article also takes a look into the future

of genome editing, including possible other technology that could function better and impact the public ethical concerns on technological misuse has on research and future advancement. The article recognizes that if public opinion does pose enough of a threat to the research being conducting on CRISPR-Cas9 and place permanent roadblocks upon it, it may pave the way for other more acceptable gene editing technologies to develop. The author comes to the conclusion and stresses the importance that continuing research will make the prospect of gene editing technology safer and much more effective, stating the inevitability of its use based on the benefits it provides.

Moreover, author Tristan McCaughey et al explores this theme in the article entitled "A Need for Better Understanding Is the Major Determinant for Public Perceptions of Human Gene Editing". This article examines the factors that influence public opinion regarding gene editing. To do this, the authors conducted an online survey that was advertised worldwide. They also discuss that there are calls from within the scientific community to place more attention on the lay opinions of everyday individuals so that it can aid in shaping scientific research. The results of this article found that the public apprehension toward gene editing was not based on an inherent mistrust of gene editing as a technology, but rather a need for greater understanding of the topic and the technology. Therefore, understanding that there is a lack of comprehension from individuals not of a scientific background, scientists must take this into account when conducting research and releasing information on it so as not to create confusion and limit the

capabilities of the groundbreaking technology. Thus, the research itself is impacted on a fundamental level in such a way that it can be translated into everyday terms for any and all individuals to digest the information and form well-rounded opinions.

Lastly, the article entitled “The Power of Science Communication”, written by Mihaela Sabina Jucan and Cornel Nicolae Jucan, further elaborates and inspects this shared theme. Similar to the previous article, this article discusses the benefits that result from effective science communication. This article states that most scientists undergo training to prepare them to communicate to other scientists of a similar educational backgrounds and are not typically accustomed to relaying their research to non-scientists. Due to this, scientists are primarily focused on how a particular discovery or technology impacts current research and do not take into account the public’s desires to know how it could impact everyday lives. Additionally, this article highlights that by tailoring their research in such a way that makes it easier for the non-scientific community to understand, scientists are taking into consideration the needs of the public audience rather than just the scientific one. Understanding this, it provides scientists with a greater likelihood that their research will be more accepted if the public has a comprehensive understanding of the research.

Conclusion

Each of these sources present a broad understanding of the issues that face the current scientific community, particularly geneticists, with the advancement of

more sophisticated genome editing technology, CRISPR-Cas9. The sources in the first category provide a fundamental basis for the understanding of the ethical issues that surround CRISPR-Cas9, which offers insight into what exactly geneticists are facing with their technology. In addition, this foundation functions in tandem with the article in the second category to shed light into how exactly geneticists and their research are impacted, especially in the long-term. Overall, these articles provide a more specific insight into the exact conversations that are taking place within the field of genetics regarding the advancement of genome editing technology, particularly with the refinement of CRISPR-Cas9.

Results:

The interviews conducted throughout the investigation process resulted in a multitude of themes and ideas related to this topic from each scientist and their perspective. However, two main themes were shared between each scientist: challenges communicating to lay individuals and effects of negative ethical opinions/stunting research development. Although each spoke about these ideas differently, ultimately, they stressed the impact these challenges place upon research and research scientists in the field. In genetics, and research science in general, public opinion has much more of an impact than one may think, especially if that opinion is negative or derived with a lack of knowledge. It may influence the pursuit of further research and negatively affect researchers and scientists. These themes set a well-rounded basis for individuals to understand how exactly ethical opinion may influence research and research scientists.

When it comes to complex scientific research, much of the published papers on groundbreaking technology and exploration, like CRISPR-Cas9, are written for other scientists to understand. Therefore, there is a lack of simplification of the research, rendering it difficult in its application to a more everyday audience. Dr. Tim Myers related this best to CRISPR-Cas9 technology by saying, "...the complexity with [CRISPR-Cas9] is a little hard to just explain to a lay person. The way to kind of talk about it would be to formulate it in such a way where you would say that we're making changes, like inside your body." Dr. Myers emphasizes the importance of constructing the research in such a way that both scientists and a lay person may read and understand it. This is especially vital for research development since a negative or uneducated opinion formed by the public may influence progress. As a scientist himself, Dr. Myers demonstrates the difficulty in explaining such complex topics and technologies, where it is difficult to bring a description down to a level where everyone can understand. His choice of framing what exactly CRISPR-Cas9 is, as a way of making changes, highlights the struggle scientists, like Dr. Myers, have when introducing their research and discoveries. Dr. Kimberly Stephens also highlighted that this scientific communication is not just CRISPR-Cas9 specific, but rather applicable to all scientific research: "[communication] is a question that we need to be working on consistently as scientists, because most of our research is not communicated well with the public...we need to do the work of educating them in the background information in a way that a layperson can understand before we start spewing off

the facts from the research we have." Dr. Stephens highlights the lack of proper education and communication with the public regarding research; as a result of this, unfounded and uneducated opinions are formed, which directly impacts the research and scientists conducting the research. Including suitable explanations and education to individuals can be frustrating, as can be felt from Dr. Stephens' response, especially since researchers are very accustomed to citing their data with the expectation that everyone will understand, when in reality, this is not the case and can most of the time come to a detriment to the integrity of the research itself if it is not understood properly. As Dr. Stephens states, scientists will "spew" off the facts, emphasizing the frustration both she and other researchers experience when releasing research to the public. Dr. Aaron Steiner also shares similar thoughts on science communication, stating: "...the question is about science outreach and science communication. So that's a different issue. How could scientists be better at communicating about these things with the public? I think that scientists have a tendency to get bogged down in the technical details of things, and we need more people who can communicate these things in general terms, and most importantly, to impress upon the public the potential value of these technologies." With the implementation of better scientific communication, the value of groundbreaking research and technologies, like CRISPR-Cas9, can be relayed to individuals to allow for further research and application. Dr. Steiner shares a similar outlook to Dr. Stephens in that scientists have a tendency to focus on technicalities and complex concepts, leaving out crucial information or details

necessary for accurate understanding. He too has a similar feeling of frustration resulting from the somewhat inflexible nature of the scientific community; without changing approaches to releasing research, the value of discoveries will never be at the level they truly are.

This lack of proper education on behalf of the researchers creates a basis for the public to form negative opinions, generating the possibility of hindering technological progress. As Dr. Myers details with reference to stem cell research that was blocked by government administration, "imagine how many lives we could have saved if these technologies had advanced at the rate they could have but now we had to wait and be like 'oh, let's create stem cells out of skin cells,' and we were able to do it like 10 years later, but now there are certain technologies that probably lagged behind about two decades." Dr. Myers demonstrates the gravity public opinion's influence has on scientific research, specifically how it may stunt development and setting back technology from revolutionizing medicine. A sense of longing and wistfulness can be felt from Dr. Myers' response, in that the original research he is speaking about could have had much potential. Related to this, Dr. Steiner also details how negative views may impact research: "And [negative opinion] could affect funding, and that could, in turn, affect the science and how fast things advance and how effectively things advance." Funding plays a major role in conducting research and if the public holds a negative view for certain technologies and research, scientists may not be given the opportunity to explore that research due to lack of funding from scientific organizations. As a

scientist and University professor, funding is an important factor when conducting research since it often comes from individuals and organizations that do not necessarily understand the research in its entirety. Dr. Steiner also details how these ethical opinions may affect research development: “I guess the question is, will negative views of this technology affect future technologies that might be developed? And I think yes. But if that weren’t the case, then when those new technologies came out, there would be people who are against them, right?” As highlighted by Dr. Steiner, public opinion has a significant effect on scientific research development, particularly if it is of a negative connotation or standpoint. Dr. Steiner’s indifferent and somewhat cynical response underscores an important aspect about this issue: no matter what changes are made to try and modify how research is presented, there will always be individuals who are against it and think of it negatively.

As demonstrated by these scientists, continuing to implement the current methods when publishing scientific research will likely only perpetuate the current issues researchers are facing when releasing their discoveries to the public. That is, excluding these individuals via language and lack of proper explanations would only reinforce the disservice to the scientific community, further adding to the difficulty of acceptance and understanding from the public. As a result of this, progress is hindered, causing the actual science and technology to be set back. This is especially vital when discussing technologies that can revolutionize certain approaches in the medical field, like CRISPR-Cas9 and as Dr.

Myers mentioned, stem cell research. As highlighted by Dr. Myers, Dr. Stephens, and Dr. Steiner, science communication plays a major role in how research discoveries and new medical technology is interpreted by the public. Additionally, it will allow for a greater chance of the research to be implemented and not cause further obstruction on development and usage.

The results of the conducted interviews align and uphold the hypothesis that negative public opinion and ethical views impact the development of scientific research, particularly genetic research, and lead scientists to improve their communication with the public. When the public is not properly educated or provided with information in such a way for them to understand it from an objective standpoint, unfounded opinions are formed. This leads to implications impacting the genetics field and causing researchers to have difficulty continuing their research. Thus, if research is framed in a way that is applicable and understandable by an everyday audience and individuals outside of the scientific community, more well-rounded opinions can be formed, leading to progress and less roadblocks for scientists. Therefore, the public's perception, especially that of a negative connotation, influences researchers and approaches in the field to improve their communication through explanations and distribution of the research in a way to make it more understandable to individuals outside of the scientific community, allowing it to be deciphered in a full capacity.

Conclusion:

Much overlap is found between current conversations in the field as seen in the literature review as well as first-hand scientist perspective in the conducted interviews. That is, the connection between the calls for ethical considerations of CRISPR-Cas9, as well as other scientific technologies, and its impact on scientific research and researchers is shared among published discussions in the field and the scientists interviewed. As mentioned by Dr. Myers and shared by authors Mihaela Sabina Jucan, Cornel Nicolae Jucan, and Tristan McCaughey et al, much of the miscommunication with scientific research, particularly those of a much higher and experimental level like CRISPR-Cas9, is a result of lack of proper education and communication of the technology on behalf of the scientists. Understanding these points, these authors along with Dr. Myers, Dr. Steiner, and Dr. Stephens, stress the importance of including sufficient background information and proper communication of scientific research so that well-rounded opinions can be formed that are not just based on a lack of understanding. Thus, considering these accounts, public opinion, especially those of a negative nature, implicates scientists and researchers to make their research more accessible and understandable to all individuals, so that it is not just geared to a scientific audience. The use of more inclusive language to render the research more comprehensible to a lay audience, will allow the opportunity for the research to be analyzed to its full extent and capacity, particularly for studies exploring genetic editing technologies like CRISPR-Cas9, where currently scientists inundate readers with various technical terminologies.

This study is especially crucial as scientific research and technology is rapidly advancing. Proper scientific communication is necessary in order for high level research to be analyzed in a correct matter; valid opinions cannot be formed if only some of the information is understood. Progress cannot continue to occur if the public is not properly educated on current research that is being released and published. Therefore, if researchers continue to write and publish their research solely for a scientific audience, excluding the scope of public scrutiny, they run the risk of negative opinions forming, possible limitations in research funding, and the stunting of research progression. Understanding this, changing their approach in sharing their advances in research, through tailored explanations to individuals outside of the scientific field, will not only benefit the public, but also allow scientists to move forward in their progress of these developing technologies.

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Reflection

After conducting peer reviews and receiving feedback throughout the drafting process, it helped me to better articulate the flow and explanations of my topic and the issues surrounding it. Through this process, it emphasized points regarding the details of my topic, such as what CRISPR/Cas9 really is and how it fits into the realm of genetics and gene editing, that were not previously clear to readers who are unfamiliar with this form of gene editing technology. An important aspect that was stressed is specificity. That is, being specific when detailing and describing my topic, especially since it is a type of technology that is not necessarily well-known outside of the scientific and STEM community, its inclusion is key for demonstrating the issues present regarding the technology to readers. Also, taking these thoughts into account, it allowed me to narrow my very complex and broad topic to a level that can be understood on a non-scientific level. In addition, in order to present the ethical issues surrounding CRISPR/Cas9, it was vital that a basic understanding of what the technology is be initially disclosed to readers such that an educated opinion can be formed. Specificity was vital when writing, especially in my literature review, where although I did reference each individual article in the subtopic categories I chose, its lack of specific points and conclusions made by the authors did not allow potential readers of the paper to understand what exactly I was intending with the use of the articles. Once additional information was added into each paragraph, it more

clearly explains the purpose of each article and allows readers to grasp the ongoing and current conversations taking place within the field and gene editing discussions. Also, in the second category of the literature review I had initially chosen only one article associated with it prior to conducting peer review. After taking into consideration my peer's thoughts on including two additional articles within this section, it made me realize that the inclusion of this would strengthen my points further and make clearer to readers my exact arguments.

In revising this draft, I found it important to construct the writing in such a way that a general understanding of the function of CRISPR/Cas9 was relayed to readers so that it seamlessly transitioned into the ethical concerns surrounding the topic, without overly complicating the subject. The function plays a crucial role in much of the apprehensions that both scientists and the public present, specifically to what length the technology could be used and the potential for misuse. As a STEM student, I needed to express the topic and its issues in such a way that others with no prior knowledge or STEM background would understand in order for the message to be conveyed. Furthermore, constructing my research questions so that they pertain to the impact on geneticists and their research, rather than the effects on the public, also played a key role in demonstrating the predicament that the public's skewed opinion places scientists in. Like the current conversations taking place within the realm of gene editing, I also needed to make sure that I took non-scientific readers into consideration when writing the sections in my paper. That is, just because I understood what I am writing about,

it does not indicate that everyone will be able to. I made sure to take this into account when revising my draft, particularly for my literature review since the readers should not feel the need to search for the articles I referenced themselves; they should be able to gain everything from my literature review that they could if they were reading the articles themselves. Overall, based on the process so far, it allowed me to better refine and articulate my points in such a way to make clear to readers in a complete and comprehensive way.