

Public Trust in Gene Therapies: A Sociotechnical Analysis to Investigate How Best to Approach Patient Education

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On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments

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Introduction

As of 2019, over 40% of diseases are known to have some form of genetic component (Lakhani et al., 2019). While modern science has become increasingly capable at curing diseases caused by external pathogens, developing long-term cures for genetic diseases, beyond simply managing the symptoms, has been more elusive. Since the turn of the 21st century, gene therapies have been gaining steam as a potentially permanent solution for patients battling genetic diseases. Gene therapies are built upon the idea of editing mistakes in a person's DNA to directly target the underlying cause of the genetic disease. While the actual mechanisms and technologies behind this process are immensely complex, the attitude of the medical research community is nothing but optimistic concerning the potential of gene therapies to broaden the scope of treatment options for patients. However, even in light of such optimism, the public has still been provided reasons for skepticism.

In 1999, an 18-year-old boy named Jesse Gelsinger participated in a gene therapy clinical trial in an attempt to treat his genetic metabolic disorder. He began the trial relatively healthy, but within four days of receiving the therapy, he was pronounced dead after a severe immune response against the therapy had led to organ failure and brain death (Sibbald, 2001). As the first person publicly identified as having died in a gene therapy clinical trial, Jesse Gelsinger's death serves as a glaring example of one often neglected critical fact: gene therapies have not existed long enough for scientists to fully explore their risks and long-term effects.

Currently, gene therapies are used primarily in clinical trials where the patients receiving them are accepting that this treatment represents a last-chance at bettering their quality of life or even survival. However, as the FDA-approval and the use of gene therapies becomes more mainstream, clinicians will need new strategies to appropriately educate and inform their

patients. Eliciting informed consent from a patient extends beyond simply communicating information about the treatment; it fundamentally hinges upon the patient performing their own risk-benefit analysis to ultimately decide if their perceived benefits of receiving the treatment outweigh their perceived risks. Patient and public trust play a significant role in this analysis, as a patient is more likely to provide consent to receive a treatment if they trust in not just the treatment itself, but in the system surrounding it as well. Factors that influence public trust in medicine have been widely researched, but it is important to acknowledge that these factors are not universal; they vary based on the situation and in this case, the treatment. Therefore, this research study aims to identify factors that impact public trust in gene therapies to inform how to best approach public education and ultimately ensure that future patients receive and believe in these revolutionary treatments.

Gene Therapies and Public Trust: Existing Literature

In an effort to narrow down the number of possible factors that can influence public trust in gene therapies, work already accomplished in this field was reviewed. Relatively short after the death of Jesse Gelsinger, a 2002 journal article by Gottweis directly addresses the topic of public trust and gene therapies. Gottweis argues that concerns surrounding gene therapies are not due to a lack of public access to scientific information, but rather a lack of public trust. In a brief investigation of the factors that impact public trust in gene therapies, Gottweis identifies the government and politics to be at the center (Gottweis, 2002). According to Gottweis, endless policy disputes and “the widespread feeling of radical uncertainty” have eroded the perceived authority and expertise of the scientific community, which promotes greater skepticism of new science (Gottweis, 2002). To restore the relationship between science and the public, Gottweis suggests increasing transparency and creating direct communication channels between the

scientific community and the public (Gottweis, 2002). Gottweis's work opens the door for understanding factors that influence public trust in gene therapies; however, successive research in the field has diminished the strength of Gottweis's findings.

Two separate studies examined the ideas of transparency and open communication in gene therapy research. A 2007 study by Barnett et al. investigated the idea that greater transparency would promote less public fear of and more positive attitudes toward new genetic technologies. Analyzing data from the 2003 British Social Attitudes Survey, Barnett et al. found a correlation between the belief that the scientific community should be more transparent and negative attitudes toward genetic therapies (Barnett et al., 2007). To summarize their findings, Barnett et al. suggest that transparency likely isn't a solution to the problem because the people who believe in greater transparency do so because they already don't trust science as a whole and are less likely to support the use of genetic therapies (Barnett et al., 2007). As a result, even if these people are given the transparency they request, they are unlikely to believe the results and still remain skeptical because of their inherent, relatively uncompromising mistrust. In a similar vein, a 2013 study by Master and Resnik explored how "hyping" new medical technologies impacts public attitudes and trust in their use. Master and Resnik concluded that by hyping genetic technologies, public expectations for immediate success are heightened and often not met, leading to a decrease in trust (Master & Resnik, 2013). Both studies weaken Gottweis's suggestions that greater transparency and open communication will promote greater public trust. However, a third study does seem to provide a specific role for open communication in the public trusting process.

In a 2001 journal article, Verma investigates the communication of adverse events through case studies of two gene therapy research incidents. In the situation of the Jesse

Gelsinger clinical trial, results from a previous animal trial predicted a relatively high probability for patient death, and yet the therapy still transitioned into human clinical trials. When the public caught wind of this evidence, outrage ensued over the fact that previously reported adverse events were not handled properly and the human clinical trial was not halted (Verma, 2001). Verma contrasts this with the actions of a research group studying the long-term effects of a different gene therapy. Having already transitioned into human clinical trials, this research group found the therapy to induce specific defects in mice that received it over a long period of time (Verma, 2001). With this result in hand, Verma describes the research group as “relentless” in making sure that the human clinical trials were put on hold until the defects were further investigated (Verma, 2001). This time, when the public was notified, the research group was praised for their integrity and communication (Verma, 2001). Verma concludes that “The best we can do is be vigilant and watchful, and communicate,” suggesting that the public seems to put some trust value in open communication, namely when things go wrong (Verma, 2001).

The existing research in the field does provide some foundation on which to build this study. However, while much of the research is devoted to identifying factors that fail to build public trust in gene therapies, not enough research addresses factors that positively influence such trust. Interestingly, Gottweis does offer a brief suggestion that the scientific community’s current mental model for “the public” needs to be “thoroughly reconsidered” because “today’s societies are socially, culturally, and politically highly diverse” (Gottweis, 2002). Gottweis does little to expand on this idea or connect it to public trust, but the door is left open for future studies to explore how increased understanding of the different social, cultural, and political aspects of society can help build greater public trust in gene therapies and ultimately benefit effective patient education. With this in mind, this study will focus on identifying and

understanding some, but certainly not all, social, cultural, and political factors that could influence public trust in gene therapies.

Methods:

While the above literature review performed well at identifying three key aspects of society to analyze with respect to public trust in gene therapies, it also highlighted a previously-mentioned challenge that this study faces. Gene therapies are still a relatively new medical technology, and as such, have not yet been studied to the fullest extent, especially with respect to any specific social, cultural, and political factors that could influence public trust. However, while gene therapies have only really existed for the past twenty-five years, the idea and the field of genetic technology has existed for much longer. Therefore, this study will slightly expand its data collection and analysis to use more established applications of genetic technologies, such as genetically modified foods and organisms, to provide insight into attitudes and beliefs the public may hold or develop toward gene therapies. Findings from the analysis of genetic technologies and public trust will be used to guide suggestions on how to best approach public gene therapy education.

Results

Social factors and public trust: A study of how we interact

In a 2006 journal article, Ganiere et al. used a U.S. national telephone survey to gauge general consumer acceptance of and attitudes toward genetically modified foods. In an effort to reveal some key factors that influence consumer acceptance, Ganiere et al. makes the statement that “the biggest threat for [genetically-modified] foods appears to be a perceived risk to human health” (Ganiere et al., 2006). The word choice of “perceived risk” by Ganiere et al. is quite

interesting, as it suggests that the acceptance of gene therapies might not be driven by the objective magnitude of risk, but rather the public perception of that risk, which could potentially be different. This study argues that public perceptions of gene therapies would be impacted by the social interactions of the American people. Specifically, this study considers the interaction between the public and news outlets and social media.

Collecting daily information from news outlets is something that essentially all Americans do. According to a 2014 study by the American Press Institute, almost 90% of Americans get news directly from news organizations (“How Americans Get Their News,” 2014). Additionally, approximately 50% of survey respondents specifically indicated that they completely/very much trust news coming directly from these organizations (“How Americans Get Their News,” 2014). Given the influence news organizations seem to have on the American public, one can wonder how they affect the public’s perceptions of medicine and medical technologies. A study by Young et al. investigated how the influence of the media can impact public perceptions of disease. The study found a positive correlation between the public’s rating of a disease’s severity and the frequency of media coverage; the more the media covered a disease, the more severe the public perceived it to be (Young et al., 2008). While Young et al. concludes that the media can bias the public’s perception of disease, they also clarify the point that the media doesn’t necessarily tell the public what to think, but rather what to think about (Young et al., 2008). This can be harmful as the perceived risk to the public can become blown out of proportion due to extended media coverage. Dougall et al. examined how media exposure impacted the public’s response to anthrax bioterrorism attacks. While anthrax is not communicable like other infectious diseases, it effectively immobilized Washington, DC for a brief period of the early 21st century (Dougall et al., 2005). Dougall et al. argued that heightened

media coverage prompted the public to focus on the situation without being guided by enough objective facts, leading to unnecessarily increased perceived risk (Dougall et al., 2005). The above findings demonstrate that while news outlets may not be directly responsible for the beliefs the public adopts, they do prompt the public to form beliefs toward medical topics that they may be ill-equipped to properly think about.

In terms of receiving news or just information in general, social media has become a top outlet in recent years, especially with younger generations. While the American Press Institute found survey respondents to indicate social media as their least trusted means of receiving news, it's hard to ignore the platform social media has given to people around the world, most notably public figures ("How Americans Get Their News," 2014). This platform has been used for plenty of good, recently helping sports figures organize monetary donations to support hourly-paid stadium employees who lost their jobs due to the Covid-19 pandemic (Wimbush, 2020). However, this platform has also been used for the spread of medical misinformation, most notably the slew of public figures who continue to circulate the belief that vaccines are harmful. The question posed here is not why public figures feel the need to spread their opinion regardless of if it's correct; that is well within their rights as Americans. But rather, why do people choose to believe and adopt public figures' opinions as their own? The work done by Frewer provides an answer to this question. With respect to evaluating information sources, Frewer says that the public employs two "dimensions" to determine if a source is trustworthy: competence and honesty (Frewer, 1999). Using this framework, the transparency of social media likely helps the public evaluate public figures for honesty, but it's hard to believe that the public finds public figures to hold medical competence. Findings presented by Frewer can explain a mental workaround for this. Frewer states that when individuals consider new information about an

attitude or belief they are currently developing, “people are more likely to assess the information [...] to see if it aligns with the view that they already hold.” (Frewer, 1999). Those who choose to believe that the information public figures spread about vaccines being harmful likely do so because they already have some skeptical belief of their own. They see this information as confirmation of their suspicions and accept it to further develop their false belief that vaccines cause harm. Why then do people fail to instead believe the vast quantity of scientific evidence proving the safety of vaccines? This study argues that while the lay person is given plenty of scientific information, they are not necessarily given the proper tools and support to understand it. Gottweis stated that conferences devoted to educating people about gene therapies were not effective because too much information was presented without enough back-and-forth discussion (Gottweis, 2002). This argument suggests a need for a trustworthy and knowledgeable “individual” with which the public can confidently converse with in order to properly develop their beliefs. In the absence of this “individual”, the public turns to vocal, relatable public figures with large online platforms because they echo a similar skepticism. The above discussion does not argue that public figures that circulate false medical information should be silenced, but rather the supports the need for greater public support and training for evaluating credible sources of medical treatment information.

Cultural factors and public trust: A study of who we are

An individual’s culture and cultural beliefs can have a large influence on their perception of medicine. As many genetic diseases are more prevalent within specific cultures (such as Tay-Sachs disease within the Jewish community), it is critically important to understand how the belief systems of different cultures influence their acceptance and therefore trust in genetic technology. Finucane and Holup conducted a literature review to identify how cultural factors

can affect the perceived risk of genetically modified food (Finucane & Holup, 2005). Individual cultures were found to exert significant influence on attitudes toward genetically modified food. Specifically, Germany demonstrates a large resistance to genetically modified foods, likely attributed to their desire to reject anything to do with genetics and Nazi culture. Various religious groups are also unapproving of genetically modified foods, as they consider editing an organism's genome to be contrary to their belief systems. Even food culture can have an effect on these attitudes. Some western European countries like the United Kingdom demonstrate skepticism toward genetically modified food because of the relatively recent fear of contracting mad cow disease from beef and milk in the late 20th century (Finucane & Holup, 2005). The findings of Finucane and Holup serve to show that cultures can develop similar perceptions of genetic technologies that are motivated by vastly different reasons. As the United States is a melting pot of many different cultures, it will be important to understand the experiences of each of these cultures and how they influence their beliefs on genetic technologies and even medicine as a whole.

A key U.S. cultural group that is important to analyze and understand is the African American community. The African American community is particularly relevant because they both have some of the worst health outcomes among different cultural groups while also expressing relatively high incidences for some cardiovascular and kidney diseases with known genetic components (Flack et al., 2003; Genovese et al., 2010; Mays et al., 2007). It will therefore be critically important to understand how the experiences and beliefs of African American culture could influence their trust in gene therapies. In a 2001-published study, Freimuth et al. set out to identify reasons behind the high reluctance of African Americans to participate in clinical and public health research. Reverberations from the infamous Tuskegee

Syphilis Study were found to be at the center of this reluctance (Freimuth et al., 2001). The Tuskegee Syphilis Study is one of the most frequently quoted examples of the abuse and mistreatment of human research subjects in the United States. In the 1930's, a large cohort of African American men with syphilis were tracked for forty years without being informed of their condition or being treated for the disease despite the availability of a cure. The Tuskegee study's egregious violations of ethical standards have since formed the basis for informed consent in all human research studies today. Freimuth et al. found that most all of their study participants were familiar with the Tuskegee study, and many were even familiar with the alterations made to modern human subject research with respect to informed consent. However, even with the reforms made to modern human subjects research, the majority of African American respondents still held a strong distrust for researchers and medicine as a whole (Freimuth et al., 2001). The results of this study show how the negative interaction between the African American community and the medical community has ingrained a sentiment of distrust toward medicine that persists today within African American culture. Additionally, Kennedy et al. found that distrust of the healthcare system is a common thread among many poor and minority populations across the U.S., especially those that experienced past instances of maltreatment (Kennedy et al., 2007). While relatively brief, the above analysis of a single U.S. cultural group highlights a need to understand how the experiences and beliefs of all cultures can influence their trust in gene therapies and medicine.

Political factors and public trust: A study of how we are governed

The confidence and trust people have in the U.S. government has been previously found to play a large role in the consumer acceptance of genetic technology (James et al., 2002). This role is thought to be derived from the public belief that the U.S. government is responsible for

public health and safety. A study by Ganiere et al. found that individuals who showed negative attitudes toward genetically-modified foods also held low confidence in the U.S. government for managing food safety (Ganiere et al., 2006). It is natural to conclude that if trust in the government is improved, attitudes will become more positive as well, but this is easier said than done. A 2018 journal article by Kettl describes how wholesale trust of the U.S. government has diminished rapidly in recent years (Kettl, 2018). “At the core of the problem, “ says Kettl, “is the fundamental problem of inequality” (Kettl, 2018). While Kettl proceeds to analyze the problem from an income and economy-based standpoint, inequality with respect to healthcare and medicine is also very real. Healthcare disparities can take the form of differences in access to high-quality healthcare, differences in the availability of affordable, wide-covering health insurance, and differences in the sheer cost of healthcare for those that are insured versus uninsured, not to mention disparities based on gender, race, and/or culture (Burgess, 2010; Moy et al., 2005; Soto et al., 2013). Individuals do not need a negative interaction with the healthcare system to develop mistrust. Following the logic presented by Kettl, mistrust can also be cultivated when individuals perceive their overall level of care to be less than others even if they initially thought it was acceptable. The findings above seem to suggest that addressing this inequality through healthcare reform will go a long way toward promoting greater trust in the government as a reliable provider of public health and wellbeing.

Regaining trust in the government is also a function of trusting the politicians who comprise the United States’ governing branches. In accordance with the classic idea of a representative democracy, a majority of the public should have confidence in the politicians in office because the public is directly responsible for the politicians’ successful election. However, as politics have become increasingly partisan, the ensuing gridlock has diminished the

public's faith that their voices will be heard and actively represented in the political arena (Dastagir, 2019). This is similar to the concept presented earlier by Gottweis that increasing non-action and uncertainty within the government has diminished the public's perceived authority and expertise of the scientific community (Gottweis, 2002). On the other side, politicians have come to recognize the difficulty of pushing legislation into law in this current polarized political climate. Instead of focusing solely on accomplishing what they set out to do for the good of their voting district, politicians have shifted toward promoting political agendas while also pursuing their own reelection increasingly early on in their terms (Rauch, 2016). This approach is not appropriate when addressing healthcare reform. During the recent Covid-19 pandemic, the U.S. House of Representatives passed a bill that would confer free Covid-19 testing for all patients. The bill was set to pass in the senate, but senator Rand Paul from Kentucky proposed an amendment that had "little to no chance of passing" simply to delay the passage of the bill (Dockery, 2020). The amendment was voted on several days later and was not accepted, and the bill ended up passing, but this served as a glaringly obvious example of the current attitudes of some of the U.S. politicians in government today. If politicians act in this sort of manner during a time of national and global crisis, how can the American people trust them to act in their best interest during relatively normal times? The public not only needs to have faith that politicians will be able to improve the healthcare system, but also have faith that politicians will demonstrate the desire and willingness to do so.

Discussion

Patient education is often thought of as something that happens between a patient and a physician inside the examination room. However, if this study has revealed anything, it is that a patient can become "educated" before ever approaching a healthcare facility. The public

perception of gene therapies will play a much larger role in influencing public trust than any objective fact about the treatment. In order to design strategies to effectively educate patients about gene therapies, the factors discussed above that influence public perception must be taken into account.

Reforming gene therapy education conferences

Establishing clear communication channels between the public and the medical community will be vital. In accordance with the suggestions of some previous studies, a step in the right direction will be increasing the availability of and changing the structure of gene therapy public education conferences (Abou-El-Enein et al., 2015; Gottweis, 2002). These conferences will be open to everyone, offering a platform from which to communicate objective information about gene therapies. The goal of these conferences will not be to sales pitch to participants and convince them that gene therapies are a cure-all treatment, but rather to give them the information they need to form their own beliefs to convince themselves that gene therapies are worth the risk. Open discussion between knowledgeable and empathetic medical professionals and participants will be encouraged so that participants can have their questions answered and the myths they hear online or in the news be debunked, while shaping their developing beliefs in a structured environment by an objective, holistic presentation of the risks and benefits.

Targeting gene therapy education to younger generations

A redesigned gene therapy education conference will be a good start at instilling trust during the present-day education process. However, it's important to acknowledge that while the majority of the anticipated attendees of these conferences will be adults, this population will likely not see gene therapies move into mainstream use in their lifetime; it is much more likely

that their children will be significantly impacted by this change. Therefore, this study argues that additional steps be taken toward educating younger generations to plant the seeds of trust early. This study recommends that this approach be pursued down two avenues. One will be to start gene therapy education in schools. It is true that a shortcoming of gene therapy education conferences would likely be that they are voluntary; only people actively seeking to learn more would attend. In contrast, by targeting students, the potential scope of education would be much greater. The material or lessons do not have to be complex, but providing the scientific foundation to begin to understand gene therapies and some of their risks and benefits could go a long way. Additionally, this study recommends that gene therapy education gain a larger presence on social media. As mentioned previously above, social media has become increasingly popular with younger generations. In order to target this population, a stronger social media presence will need to be competent and honest, in line with Frewer's framework for evaluating information sources described above. To address competency, this study recommends having relevant stakeholders in the medical community such as medical professionals and pharmaceutical companies increase their activity on social media. This suggestion is not to be interpreted as large, faceless companies creating social media profiles and periodically posting facts about gene therapies, but rather representatives of these organizations using social media to interact with people online and give these companies some form of human characteristic. Building positive relationships with a social media base will certainly build competency and honesty, and through both of those, trust will hopefully be fostered.

Addressing cultural differences and politics

Now that a plan for communication has been outlined, the question becomes who will be responsible for initiating and sustaining this communication? This study suggests that the teams

of individuals tasked with carrying out public outreach be as diverse as the public they are serving. Individual cultures and their beliefs differ widely in their perception and acceptance of genetic technologies and gene therapies. Having individuals who are part of these cultures helping to communicate with and educate the public will be invaluable, as they will likely understand how best to appeal to members of their own culture to ensure that information is optimally delivered. Additionally, simply having members from an individual's own culture advocate for gene therapies alone may be enough to promote some level of trust in these therapies. By embracing diversity in communicating with and educating the public, some of the inequality referenced by Kettl above may be mediated. However, in order to fully address inequality, specifically healthcare inequality, large-scale changes will need to be made to the healthcare system. The majority of the suggestions by this study can be implemented in the relatively short-term; however, the political and policy changes mentioned above will likely not happen in the near future. Reducing the disparities in healthcare could have a significant impact on improving trust in the government, which could contribute to increased trust in medical programs and treatments it supports, such as gene therapies. However, sweeping changes to the American healthcare system will not be possible until political gridlock and polarization are decreased. Future studies will need to address ways to combat partisan politics and potentially develop workarounds to begin making positive changes to the healthcare system as soon as possible.

Conclusion

Gene therapies are a potentially powerful tool of the future, but many sociotechnical factors pose to influence their public perception. In an effort to understand how to best approach gene therapy education, this study sought to investigate how social, cultural, and political factors

impact patient trust in gene therapies. The aspects of society that the public interacts with, namely news organizations and public figures on social media, were found to exact a significant influence on the information that the public focuses on and develops beliefs about. In addition, cultural groups were found to harbor widely varying beliefs about genetic technology, often influenced by past interactions with medicine. Finally, trust in the government was found to be strongly correlated with trust in genetic technology, as the government is held responsible for promoting the public's health and wellbeing. From all of these findings, key suggestions were made toward approaching gene therapy patient education. Significant changes to the structure of traditional gene therapy education conferences were suggested. Recommendations for how to target America's youth in an effort to provide a foundation of trust in those who will likely be influenced the most by gene therapies were made. Finally, individuals responsible for communicating with the public were suggested to be recruited from diverse backgrounds as to optimally connect with the public, while recommendations for future studies to address healthcare reform were provided. Gene therapies possess immense potential to improve the quality of life for millions of people living in the United States, but all that potential will go to waste if people do not trust and consent to their use. It is hoped that with this study, a step in the right direction is made toward establishing effective protocols for properly educating the public about gene therapies.

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