



## Research article

# Researchers views about perceived harms and benefits of gene editing: A study from the MENA region



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## ABSTRACT

**Background:** The development of gene editing technologies is very promising for the treatment of genetic diseases. However, gene editing can be also used to enhance the characteristics of healthy individuals. This study aims to determine ethical challenges that may face the constitution of gene editing in the Middle East and North Africa (MENA) region.

**Methods:** An online discussion forum about the ethical challenges of applying gene editing technologies was held. The participants were a group of researchers (n = 28) from the MENA region.

**Results:** Most of the participants agreed on the importance of gene editing for the treatment of genetic diseases. However, participants had concerns regarding the use of gene editing to enhance the characteristics of healthy individuals such as athletic abilities and intelligence. Among ethical issues that were raised are justice, harm, beneficence, discrimination, conflict with religion and culture, and lack of regulations.

**Conclusion:** Several ethical issues were raised for using gene editing technologies based on the perception of biomedical researchers from the MENA region. Therefore, the scientific community and other interested bioethical, social, legal, and governmental parties should be provided with a detailed guide from the scientists in this area for future uses of this technology.

## 1. Introduction

The evolution of genetic technologies has made it possible to modify somatic and germ cells (Sung et al., 2012; Kimbrel and Lanza 2020; van Haasteren et al., 2020). Scientists have recently used gene editing tools to efficiently edit the human embryonic genome (Huang et al., 2020; Karimian et al., 2020). Gene editing focuses on a specific region in the genome leading to the altering of harmful loci that cause diseases (Mehravar et al., 2020). It is intended that the next generations should inherit these alterations to eradicate mutated genes that cause diseases. The applications of gene editing in the human zygote to correct genetic diseases such as beta-globin gene disorders were reviewed (Tang et al., 2017). According to Sharma and Scott (2015), the deliberations among leading scientists concerning possible ethical issues of gene editing and the way to impact coming generations, increasing the global concerns on challenges such as, will gene editing produce designer babies?, who will choose the destiny of a child resulting from the technology?, is there a ground for the child to decide/consent?, and will people begin using such techniques to improve their abilities?

The extent of achievement of the scientists using gene editing in humans highlights the need to develop ethical guidelines that regulate this area of research (Lanphier et al., 2015; Vogel 2015; Peng et al., 2016). Scientists currently suggest that a cure can be attained at the somatic cell level since using gene editing in germ cells might lead to unpredictable results. According to Reardon (Kaye et al., 2009), there is an urgent need to develop ethical guidelines for future human genetic engineering research. In fact, due to the accelerated developments in gene editing, there is more amplification of ethical issues with emerging new questions (Kaye et al., 2009). Consequently, it is not strange to find significant studies focusing on gene editing related ethical issues, such as justice, harm, culture, religion, beneficence, discrimination and governmental regulations (Doudna 2020; Niemiec and Howard 2020; Zhang et al., 2020). Due to these reasons, this research aimed to determine ethical challenges that may face the constitution of gene editing in the Middle East and North Africa (MENA) region. Possible issues were examined by a team of scholars from the region representing various biomedical fields. The study highlights the importance of gene editing and certain ethical challenges associated with this technology among

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researchers and health care professionals in the MENA region. All presented revelations contained few problems that may be adopted to build an effective gene editing research in the MENA. Moreover, the researchers agreed that such work could energize policymakers and stockholders in creating an effective and legitimate genetic editing structure.

## 2. Methods

### 2.1. Study plan

This study used a thematic qualitative design by imagining an ethical situation. A situation in this study was to suppose that, in the future, gene editing becomes routine clinical practice for the treatment of diseases. This inspired the authors of this project to ask: What are ethical issues that might be associated with gene editing technology? Should we restrict gene therapy to the treatment of human genetic diseases? These questions were asked to a group of researchers from Jordan and MENA through an online discussion forum. The forum was part of the activities of the "Ethics of Genetic and Clinical studies" course that was offered by the Research Ethics Education Program in Jordan. All participants in this program ( $n = 28$ ) were confronted in this forum, consisting of nationalities from the MENA region. These include Jordan, Iraq, Tunisia, Sudan, Morocco, Yemen, Gaza, and Algeria. Few of the participants ( $n = 4$ ) were research assistants with a master's degree, whereas the rest were faculty members with a Ph.D degree in health-related disciplines (pharmacy, medicine, dentistry, nursing, and applied medical sciences). Among the participants, four researchers were specialized in molecular genetics with long experience in the conduction of human genetic studies. Researchers were chosen from different biomedical fields to get a comprehensive view of the studied topic.

The forum was inaugurated with a period of 14 days, and 92 posts from 28 members were tallied. The main themes that resulted from these posts were 1) Justice, 2) Harm, 3) Beneficence, 4) Discrimination, 5) Respect of culture and religion, and 6) Legislations and laws. All posts from the participants in this forum were followed and reviewed by guiding researchers. An expert in qualitative studies checked each discussion. This observing procedure incorporated elevating the members to be occupied with the conversation by utilizing a few posts like "your point needs more clarification" and "could you explain your opinion more" to confirm the partners' perceptions. These questions increased the truthiness of the collected information. To improve the investigation's objectivity, another investigator not taking part in the conversational discussion checked the collected information.

The IRB at the Jordan University of Science and Technology (IRB-JUST) endorsed this research. Alongside, IRB ensured that the ethical principles are followed, which is based on the 1964 statement of Helsinki and the principals' further modifications.

## 3. Results

A selected team of researchers residing in the MENA region discussed ethical issues related to gene editing using a web-based portal. The main ethical issues that emerged from the discussion were justice, harm, beneficence, discrimination, respect culture and religion, and regulations and laws.

### 3.1. Justice

Another concern for using gene editing is the justice of using such expensive technology. The male participant (MA, 38 years old and Muslim) mentioned "gene editing may cause biases in benefit distribution, due to the limited convenience and high costs of such technology for the public". Another female participant (SA, 43 years old and Muslim) added "genetic editing technology will be focusing on rich people and ignoring poor people". Furthermore, the male participant (AA, 36 years

old and Muslim) mentioned "applying gene editing technology will cause rich people to have more advantages than poor people to treat their diseases". Another male participant (OK, 43 years old and Muslim) added "if an athlete used gene therapy to enhance the strength of his muscles by 5–10%. This will make a big difference in sport competitions between countries ...". Female (EM, 37 years old and Muslim) added "there is an organization called The World Anti-Doping Agency (WADA) to detect the use of this technique among athletes. However, this agency is facing a lot of challenges in determining whether gene therapy was used or not."

### 3.2. Beneficence

Most of the researchers emphasized the beneficence of gene editing technology in the treatment of genetic diseases. The ALA participant (35 years old and Muslim) said "gene therapy could be very helpful in the future. We could use this technology for either prevent or treat genetic diseases, some types of cancers, and certain viral infections". Another participant (OA, female and Muslim) added: "This technology as multiple medications or surgical procedures that are used to make people behave better, look better and so on. Use of gene therapy may look equivalent to these medications and procedures". Furthermore, the female participant (SA, 43 years old and Muslim) mentioned "Applying "Gene Therapy" to cure or prevent certain diseases after careful studies where benefits outweigh risks is ethical."

### 3.3. Harm

The associated risks of gene editing were a major ethical issue highlighted by most participants. For example, a male participant (AA, 36 years old and Muslim) said "I think that we should restrict gene therapy to treatment of genetic diseases as that the entire world would agree on that .... Gene editing for enhancement purposes might introduce a new disease that could be more fatal than the one to be treated". Another female participant (HA, 35 years old and Muslim) said "There are people who are willing to put themselves at risk of gene editing to get a 5% modification in whatever area they are after, be it cognition, sports, strength, etc...". Another male participant (NM, 31 years old and Muslim) mentioned that "there are attempts to alter or improve a 'normal' person by gene manipulation, which might not be ethical." One male participant (MF, 30 years old and Muslim) pointed that gene editing might affect genetic diversity in the human population "Gene therapy could be used to select some characteristics for the newborn babies that are preferred in the community. This could result in having all human looks the same and preventing the natural selection".

### 3.4. Discrimination

Participants insisted that gene editing could lead to sex discrimination. For example, a female participant (ANA, 39 years old and Muslim) said "Genetic could result in having a gender imbalance in some societies. For example, boys are preferred over the girls in Arab countries".

### 3.5. Respect culture and religion

Respect for culture and religion is a major issue facing using gene editing. A female participant (TA, 34 years old and Muslim) mentioned that "Genetics technology is not accepted or allowed in Islam". Another participant male (HA, 35 years old and Muslim) added "Religion alongside culture in our society has to take a strong educated stance with regards to such research, prior to its advancements infiltrating and affecting our societies, to protect us and to recognize wrong from right early on. A female participant (MA, 45 years old and Muslim) mentioned "Most people are seeking for quick treatment for their diseases/conditions, but new methods are not easy to be applied in our Arab countries, it still needs more time to be understood."

### 3.6. Regulations and laws

Researchers highlighted the importance of having guidelines that regulate research activities in Jordan and the MENA. A female participant (AYA, 37 years old and Muslim) mentioned "I believe that strict regulations should be applied to gene therapy in order to restrict its use to people who are in actual need of it". A female participant (LA, 42 years old and Muslim) added that "I would think that its use shall be regulated as the use of already available techniques (ex, plastic surgery) without total prevention or restriction for medical use only".

## 4. Discussion

This was the first study in the MENA region regarding ethical issues of gene editing. The ethical challenges that might face the establishment of genetic editing in the MENA were discussed among a group of researchers from the region. These researchers were chosen from various biomedical fields to get a comprehensive view of the studied topic. Among the highlighted ethical issues about gene editing were justice, harm, beneficence, discrimination, respect culture and religion, and regulations and laws. The results of this study provide the scientific community and other interested bioethical, social, legal, and governmental parties with a detailed guide for future processing and use of this technology.

According to the current study, many respondents (75%) stated that the issues concerning gene editing are challenges associated with justice. Biases in benefit distribution, due to the limited convenience and high costs of gene-altering techniques for the public, may widen the disparity between various groups, and increase the impacts of genetic variations between individuals. Additionally, this may result in a dislike of genetic research. The 'justice' principle is a central ethical and health equity foundation that led the execution of gene editing studies and use in clinical treatment. According to the National Academy of Sciences (NAS) report (Neufeld and Scheck 2010), justice is a guideline that "requires similar handling of similar instances, and equal distribution of risks and benefits (distributive justice)".

Responsibilities that emerge from adhering to this regulation include equal sharing of research benefits and difficulties; and broad and equal access to the clinical application benefits of editing the human gene. Patients and families of individuals suffering from the sickle cell and inherited blindness expressed equality and justice as a dominant theme (Bonham and Smilan, 2018). In various studies, stakeholders were concerned about who the actual beneficiary of gene editing would be (Bonham et al., 2010; Bonham and Smilan 2018).

Another concern regarding harm is the application of genetic editing on a person and society. Besides, respondents were concerned that this technique could have unpredictable impacts on human health or could be abused. Some respondents (34%) were afraid that unethical scientists or physicians could exploit weak patients; they reiterated an oversight need during this technology implementation. "I think this testing (gene editing) can produce some undesirable side effects which may cause worse problems than what you are suffering from" (Hildebrandt and Marron 2018). Although it was apparent that the majority of discussion forum respondents had limited genetics/gene-editing method knowledge, the participants expressed similar ethical concerns to the cited published literature on the general public attitude, including the progressing consultation by academic, industry, and government partners (Haga and Beskow, 2008).

One of the most concern in our study was beneficence in applying gene editing to individuals and society. This was similar to the past work, where research revealed that in general, there was approximately 60–70% level of acceptance for therapeutically centered gene editing (Hoeyer et al., 2004; Veit, 2018). The key differences seem to lean on the proposed gene editing applications (e.g., a therapeutic strategy compared

to nonmedical or improvements). For instance, the Pew research showed that 72% backed gene-editing treatment of an acute illness will affect a baby during birth; 60% will minimize the possibility of a severe disease that may happen in an individual's life; and 19% will increase the intelligence of a baby (Balica, 2019). A study in the UK revealed that 83% of participants will back gene editing if were a carrier of a genetic disorder and there was a risk for the future generation inheriting the disorder. Yet, only 23% backed the use of gene editing 'to improve the intelligence of future children and 12% supported it to 'alter the appearance of future children (2014).

Lastly, in qualitative research meant to evoke gene editing opinions on human embryos and somatic gene treatment, focus group respondents in the upper Midwest USA produced similar outcomes in assessing the wider public (Ormond et al., 2017). Generally, the discussion forum respondents in the current study supported the application of gene editing to cure severe or life-threatening congenital or adult-onset illness but were more uncertain about applying gene editing to cure multifactorial diseases that could be treated by modifying lifestyles.

The current study reported a concern that gene editing might lead to sex discrimination as boys are preferred over girls in Arab countries (Obermeyer and Cardenas, 1997). This might create an imbalance in the population, which already started to arise in some Asian countries that favor boys but is less likely in Western Europe and North America (Macklin, 2010). Thus, gene editing technology should be regulated to avoid such discriminations and to prevent undesirable consequences in the communities.

Another ethical concern of gene editing that was discussed by other studies and was not highlighted by the current study participants is related to discrimination against disabled children (Giorgini et al., 2015; Sparrow 2019). For example, gene editing procedures could affect evolution, both socially and scientifically, and the negative effect of losing societal heterogeneity, a kind of 'counter-eugenic logic (Giorgini et al., 2015; Sparrow, 2019).

Many participants in the current study stated religious and cultural concerns about gene editing. Literature provides limited research concerning the association between spiritual connections and providing gene editing information (Sanderson et al., 2017). The two leading Jordanian religions are Islam (primarily Sunni) then Christianity (usually Orthodox). Individuals of these faiths seek religious guidance on their daily life issues and focus on matters allowed versus not allowed in their religions (Aham et al., 2014). Strict Muslim researchers have revealed that Islam embraces the exploration of gene editing foundation and highly credits the independence and privacy code (Alahmad and Dierickx 2012). According to the Islamic point of view, the main argument against embracing gene editing is that it is changing God's creation (taghyi rbi-Khalq Allah). The devil promises that "And I will instruct them, and they will change what God has created!" (Qur'an, 4:119). Modifying God's creation means apparent disobedience of a proscription that originated from the Qur'an (Lala 2020). Before delving into how and if gene editing changes God's creation, we must first be sure which verse is so firmly and steadfastly adduced to in all issues of human alteration. Altering God's creation involves not only physical modifications, but also involves teleological, and synderesis modifications that may attend the physical changes, and cannot be eliminated. A fundamental interaction principle is that adjustments, though physical, can have psychological impacts. An interest to follow a particular direction can simultaneously result in a primordial possibility, and a readiness (isti'dād) in Akbarian parlance (Lala, 2020), which may be present in the genetic constitution. Thus, modifying human genes not only alters who we are in a physical sense but also, results in an ontological change that is against culture and religions for many faiths.

Many participants in the current study stated that it is necessary to legislate and enact laws to monitor the use of genetic materials. Researchers stated that there is an urgent need to track the moral issues and

regulations concerned with gene editing. Many founders and gene editing staff, specialists, researchers, and research assistants in Western countries such as the USA and UK have considered gene editing to be a contentious investigation industry (2014). Currently, there is a lack of systematic and extensive evaluation or quality appraisal for the decisions that the individual research ethics board makes. Besides, there are no jurisdictions for committees evaluating such research to use a particular yardstick. Those who violate these guidelines and regulations do not face a criminal penalty. However, some physicians, attorneys, and biochemists are attempting to escalate these to low levels with related criminal punishments.

Scientists in China have appealed for the enforcement of clear laws and regulations to control research in human gene editing, as well as determining the kinds of research that can or cannot be conducted. From their perspective, they have been concerned that the right basic research may promote ethical discussions and thus hindering research with beneficial scientific and ethical quality.

Although restrictive laws regulating embryo research and gene alterations still exist in many countries such as China, some nations permit basic studies or have processes that allow such studies, e.g., the UK, China, and Sweden (Callaway 2016). According to Reardon, the NIH in the US has stressed its prohibition of utilizing federal financing for gene editing of human embryos due to the issues surrounding the human embryos ethical status. Such research is allowed without funding from the federal government. According to previous research, the US public appears to have a conservative perspective towards gene editing (Winickoff, 2007).

This traditional perspective may lead to more restrictions in the US compared to China and the UK. After the publication of the work of Dr. Huang, a consensus conference was convened in Washington DC in December 2015, with delegates from China, the USA, and the UK (Olson et al., 2016). After the summit, a statement lifted a worldwide suspension of all human genetic editing research, permitting fundamental research progress, but agreed on the prematurity of any clinical use. Overall, the continuing discussion regarding human gene-editing research for non-reproductive use is majorly about gene editing safety issues, because based on the existing biology knowledge; there is an extremely high ratio of risk/benefit of editing the human gene (Olson et al., 2016).

There are still high rates of unintended modifications in gene editing and other unintended impacts. Scientists are progressing on minimizing gene editing risks, thus, there is an urgent need for gene editing regulations. After the second international conference on gene editing, the summit statement, conducted in Hong Kong in November 2018, offered hopes of establishing thirteen ethical concerns in editing human genes: a viewpoint and route towards the clinical application of embryo gene editing (Olson et al., 2016).

## 5. Conclusion

The participants of the current study representing various countries from the MENA region, and different biomedical fields agreed on the importance of gene editing to treat genetic conditions. They also highlighted the need for regulations to prevent the misuse of gene editing technology. Among the raised concerns regarding gene editing in the MENA were justice, harm, beneficence, discrimination, and governmental regulations. Therefore, the scientific community and other interested bioethical, social, legal, and governmental parties should be provided with a detailed guide from the scientists in this area for future processing and use of this technology.

## Declarations

### Author contribution statement

Sawsan Abuhammad, Omar Khabour, Karem Alzoubi: Conceived and designed the experiments; Performed the experiments; Analyzed and

interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper.

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### Data availability statement

The data that has been used is confidential.

### Declaration of interests statement

The authors declare no conflict of interest.

### Additional information

No additional information is available for this paper.

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