QUESTIONS ON ETHICS AND BEYOND IN SCIENCE EDUCATION — EXPLORING THROUGH THE LENS OF GENE EDITING

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Science has brought about unimaginable technological advancements, which have benefited humanity in numerous ways, such as in the field of communication, transport, healthcare, food production, etc. Of these, genetic engineering in general and gene editing in particular are such areas that have opened endless avenues to address health-related issues. However, such remarkable advancements have also brought in ethics-related questions, which are found to be addressed inadequately in the science curriculum. The bigger and philosophical questions such as 'to what end?' or 'what is our ultimate goal?' are overlooked in science classrooms. When such fundamental questions are critically discussed in science classrooms, it is likely to guide or direct how we do science and thereby our research and innovations. This article explores such questions on ethics and even beyond ethics in science education by using gene editing as a context. It argues the need to engage students on those questions so that they are not only aware about those critical questions but are also able to take informed, ethical and responsible decisions as researchers, scientists, engineers, policymakers, etc. Some suggestions on how such concerns can be integrated and addressed in science education have also been provided. The National Education Policy 2020 has also recommended such ethical considerations.

Keywords: Gene Editing, Science Education, Ethics, School Education, Curriculum, NEP 2020

Introduction

Science has brought about unimaginable technological advancements, which have benefited humanity in numerous ways, such as in the field of communication, transport, healthcare, food production, etc. For example, humankind has benefited to an astounding scale due to innovations and inventions in science and technology; and in healthcare with the introduction of new drugs and vaccines; improvements in monitoring, diagnostic and surgical devices and instruments; application of robotics and the list goes on. Just in a span of a few decades, developments in healthcare have taken place by leaps and bounds from gene cloning, recombinant DNA technology, stem cell culture, organ culture and the latest being in the area of gene editing or genome editing. However, such remarkable advancements have also brought in ethics-related questions (Shimray, 2017). In this regard, previous researches have advocated the need to address ethical aspects in science education (Sternäng and Lundholm, 2011). Yet, the way content related to ethics has been included in the school curriculum continues to be found to be superficial, often limited to the topic of 'Ethics Committees' (NCERT, 2006, p. 184; NCERT, 2019, p. 139; NCERT, 2023, p. 203). The bigger ethical and philosophical questions such as 'to what end?', 'what should be allowed?', 'who should decide what should be

allowed?' or 'what is our ultimate goal?' for all such technological innovations and inventions are overlooked in science classrooms. Nevertheless, with the implementation of the National Education Policy 2020 (NEP 2020) such discrepancies can be addressed as NEP 2020 clearly spelled out that "Students will be taught at a young age the importance of 'doing what's right' and will be given a logical framework for making ethical decisions." (MHRD, 2020, p. 16). In line with this, the article explores concerns related to ethics and beyond ethics and why it is important to make it an integral part of science curriculum and how science education can cater to this. To do this, gene editing has been taken as the topic for the discourse for this article as we shall see in the following sections.

Prospects of Gene Editing

Today, asking what gene editing can do is almost becoming a redundant question. Rather, a more appropriate question would be, what is that gene editing cannot do? The enormous possibilities gene editing offers in terms of fixing the flaws in our body are beyond our imagination. Gene editing has the potential to prevent, treat or even cure diseases by way of faster, more accurate diagnosis, more targeted and prevention of genetic disorders. It adds and corrects genes as well as performs other highly targeted genomic modifications (Li et al., 2020). Using this approach, mutations or genetic differences causing disease can be corrected, therapeutic genes can be added to exact genomic locations and harmful genes or sequences can be removed (Dwivedi et al., 2022). It has been observed that somatic gene therapies, which involve modifying a patient's DNA to treat or cure a disease, have been successfully used to address HIV, sickle cell and transthyretin amyloidosis. Further, the technique could also vastly improve treatment for a variety of cancers (WHO, 2021). The application of gene editing using the recently developed technology known as CRISPR/Cas9 system (Clustered Regularly Interspaced Short Palindromic Repeats/CRISPR-associated protein 9), which has numerous advantages over the older gene-editing tools such as zinc-finger nucleases (ZFNs) and transcription activator-like effector nucleases (TALENs) has revolutionised the healthcare sector and is becoming a game changer. With gene editing, many of the diseases and conditions that require treatment today may not be required some day, quite possibly soon. For example, many of the heritable genetic diseases such as haemophilia, thalassemia, cystic fibrosis, sickle cell disease, etc., which are still a major concern in the healthcare sector could be fixed after birth and carriers of such diseases could be free from them and if such changes are made in the germ cells of all carriers, then such diseases will no longer exist eventually in the population. In fact, the U.S. Food and Drug Administration has already approved the use of two gene therapies in the United States, one such therapy is to improve vision in people with inherited retinal diseases and the other therapy pertains to treating spinal muscular atrophy. Several preclinical/ clinical trials are in progress which use the CRISPR/Cas system for treatment, for reversing genetic diseases or for correction of genetic codes including therapies for the treatment of cancer, macular degeneration, etc.[1] (Liu et al., 2021).

[1]Cleveland Clinic. Gene therapy. https://my.clevelandclinic.org/health/treatments/17984-gene-therapy (Accessed on 12 March 2024).

With all the endless possibilities that gene editing offers, our future is full of hopes, health-wise. No more genetic diseases, improved memory, no more deaths from cancer, no more aging, increased longevity and flawless perfect bodies are no longer a figment of our imagination but are all theoretically possible today and could be a reality at some point. 'Perfect' embryos could someday be designed. We might soon crack the code to live forever unless lives are cut short by an accident or by deliberate means, which could be self-inflicted or inflicted by others. Whatever we would imagine for sci-fi movies, we could see and experience, if not in our lifetime, soon. It surely is an exaggeration at the moment but is not impossible.

Gene Editing and Ethics in the Existing Curriculum

Science classrooms have been focused on the 'whats' of gene editing, such as 'what is gene editing?', 'what process is involved in gene editing?' or 'what are the applications of gene editing?' (NCERT, 2023, pp. 86–89). As much as gene editing is already doing wonders and giving hope to humanity to see the deadly genetic diseases vanish from the face of the earth, there are ethical issues as well as issues beyond ethics that are associated with it. The ethical issues are related to the 'whys' of gene editing such as 'is it to develop an improved human race?', 'is it to alleviate suffering caused by diseases?', 'is it to produce babies with our desired features?—beautiful, intelligent, taller, stronger, slimmer, more athletic, more melodious voice, heat and cold tolerant, etc.', or 'why should we allow or restrict gene editing of somatic or germinal cells?'. The questions beyond ethics include the bigger and philosophical questions that need to be addressed, for example, 'to what end are all the innovations and inventions?', 'what is our ultimate goal?', 'where should innovations and inventions not interfere in our body?' or 'which features or characteristics of humans should we leave sacred?'.

The discipline of science has been found to overlook much of the above-mentioned questions related to ethics and those beyond ethics, considering it as a topic beyond the purview of science (Shimray, 2017). Surely, they are not science concepts. However, we will agree that the way we answer such questions will, in a significant way, guide or direct how we do science and thereby our research and innovations. Hence, it is critical to discuss them in a science classroom. And as they say, science is directed by the worldview of scientists, with students being the future scientists, it is more so crucial to consider the topic of ethics and those beyond ethics in science classroom.

As we introduce students to questions on ethics and beyond ethics, it will guide them in their thinking about what is ethical. When such questions are raised, opportunities will be created in science classrooms for students to be engaged in critical thinking, discussion and debate, so that, they are aware of what is happening in the world in general, and the scientific world in particular. And as they understand what is ethical, they will be able to better appreciate not just gene editing but innovations and inventions in general, and in turn, will make them better innovators and inventors. They will be able to take informed, ethical and responsible decisions in future in different capacities—policymakers, researchers, engineers, scientists, etc., of course, ethics has been and is part of the

science curriculum, be it in high school, college or university. However, the aspects of ethics that are dealt with in such courses are mostly to do with equity and guidelines on the use of some organisms or some cells (NCERT, 2006, pp. 184–185; NCERT, 2019, p. 139; NCERT, 2023, pp. 89–90, p. 203, pp. 214–215, p. 225). It is limited to setting boundaries for the practical procedures related to gene editing such as 'what should be allowed.' They are invariably included right after the gene editing or related concepts and their applications and they are approached in a very shallow, superficial and linear manner. For example, what is normally included in a high school curriculum is about whether it is right or wrong to use the embryo as a source of pluripotent stem cell or embryonic stem cell for that matter or whether it is right or wrong to use certain animals or organisms for various tests and trials, or which genetically modified organism (GMO) should be introduced, etc., more so in the context of the regulatory bodies and committees that decide on ethical concerns (NCERT, 2006, pp. 184–184; NCERT, 2023a, pp. 89–90). For example, textbooks often mention of the GEAC (Genetic Engineering Approval Committee), set up by the Indian Government, which will make decisions regarding the validity of GM research and the safety of introducing GM-organisms for public services (NCERT, 2006, p. 184) whereas addressing ethics-related questions should be more philosophical in its nature and approach as it requires more critical discourse, such as 'what is our ultimate goal or motivation of such innovations and inventions?'. Such questions which will have implications in the nature or essence of humankind itself, hardly find any space for discussion. Unless we know our ultimate goal or motivation for gene editing, it is impossible to even decide on what is right or wrong, ethical or not ethical about using embryo or introduction of different GMOs. Surely, in the undergraduate biotechnology course, ethical concerns are dealt with in more detail[2]. However, even then, they are overlooked in science classrooms and the bigger questions do not seem to find space and time most probably because the topic is considered to be beyond the purview of science subject. Indeed, they are not science concepts. Nevertheless, if not in science classrooms, where else will such critical discourses happen? When will students get the opportunity to think about those questions? Discussing the bigger questions is not just for the sake of discussion but such discussions are likely to have more serious and crucial implications. It could guide students' research, their innovations, their decisions as policymakers, etc. Students who have not thought through the questions of ethics and beyond ethics could be tempted to conduct research to satisfy their wild imaginations, without considering the impact on others. Emphasis on ethics in science classroom might stop some of such research, if not all, from being conducted.

Questions on Ethics in Gene Editing

There are several aspects on which the questions on ethics related to gene editing can be discussed. It can be related to equity, purpose, limits and boundaries for gene editing and awareness of the stakeholders (including the public who are beneficiaries) about the impacts and implications of gene editing.

[2]UGC Choice Based Credit System B.Sc. (Hons.) Biotechnology. https://www.ugc.gov.in/pdfnews/1264355_B.Sc.-Hons-Biotechnology.pdf (Accessed on 12 March 2024).

1. Equity: It is one such aspect that has a lot to do with ethics as benefits brought about by technology, such as gene editing are not accessible, for example, due to high-cost associated with it. Keeping this in view, Tedros Adhanom Ghebreyesus, WHO Director-General rightly pointed out that the full impact of the benefits of gene editing "will only be realised if we deploy it for the benefit of all people, instead of fueling more health inequity between and within countries" (WHO, 2021). However, it is clearly evident from our everyday personal experience that the benefits of the majority of inventions and innovations, not only in the area of healthcare but in every sector are restricted to those who can afford. This need not be if all decisions were taken ethically—from design thinking to production to cost (price) to availability to accessibility to policy. Even without gene editing, there are several diseases for which treatments are already available. The issue is affordability and accessibility. The poor continue to die from many diseases for which treatments are already available, such as different types of cancer, thalassemia, kidney, liver diseases, etc. Sadly, they die even before the treatment commences just because they are too expensive and not affordable. On the other spectrum, those who are financially sound can 'buy life', at least to the possible extent. This is one probable reason for the increase in conflicts in our societies. If affordability is considered a top priority in design thinking during R and D (Research and Development), conflicts arising out of inequity could be minimised. Of course, once the product is launched in the market, competition brings down the cost invariably. However, this is not the case with treatments or devices which are not common or in huge demand. For example, "Drugs for 'orphan diseases'[3] are particularly difficult and expensive to develop and have a high price tag when they eventually come to market as pharmaceutical companies attempt to regain the costs of their investments. No individual patient can bear the cost of indefinite treatment so they will require a governmental approach to funding such treatments. Bearing the costs of expensive treatments for a very small number of individuals is particularly problematic in countries in which addressing communicable diseases continues to be a major public health issue and in cases, where the investment of similar amounts of money required for a single patient's treatment would see large-scale immunisation programmes completed" (Katelaris, 2014). So, the question is, shall we leave those with 'orphan diseases' on their own mercy? Are all lives equally valuable, or some lives more valuable? This is the bigger question that we want students to contemplate on, not just so they know, but so that, they can contribute in solving such challenges as researchers, scientists, engineers, policymakers, etc.

2. Purpose: Purpose of gene editing is another question pertaining to ethics. Is alleviating pain and suffering due to diseases really our goal for applying gene editing technology in the healthcare sector? Or is our purpose 'to develop an improved human race'? (Shimray, 2017) so as to create humans that are stronger, more intelligent, more beautiful, taller, slimmer, with melodious

[3]This term has been used to denote neglected disease, for example, Fabry's disease, alveolar echinococcosis, and even some common conditions such as endometrial cancer and diabetes in preschool children. However, it is more often used as a synonym for rare diseases, although some rare diseases respond to drugs that are not orphans. https://pmc.ncbi.nlm.nih.gov/articles/PMC1502161/ (Accessed on 4 December 2024)

voice, who are heat and cold tolerant, less sleep-needing, more muscular, more athletic, etc.? Is an à la carte gene editing (where one can pick and choose which gene they wish to get edited) in the offing? If that were to become a reality, the question would still be how strong, how intelligent, how beautiful, how tall, how muscular, how athletic, etc.? There will be no end to satiate our crave for 'improvement'. Are we going to bring back a kind of eugenics[4]?

3. Limits and boundaries for gene editing: This is another critical area concerning ethics. How far should we allow gene editing? Shall we remove all restrictions if concerned with somatic cell gene editing and put restrictions on interfering with gene editing that involves germline? How about the role that gene editing can play in interfering with the natural process of evolution in case germline editing is practised rampantly? When do we say that it is not ethical in terms of disrupting and manipulating human evolution? Of course, we have been doing that with animals and microbes in the lab. Where do we stop when it comes to our kind—humankind? If we intensify our interference and manipulation of the germ cells, could it some day impact the existing diversity that is seen in *Homo sapiens sapiens?* If so, how could this impact the population dynamics?

4. Exclusion of stakeholders, especially the 'beneficiaries' (within inverted commas because they might not necessarily benefit out of it) in decision making, or keeping them uninformed is also a matter of ethics. Stakeholders need to be made fully aware of what they are getting from such use of tools as gene editing. While it might just be enough to get the consent of the person for somatic cell gene editing, it would involve serious ethical considerations when it is related to germline gene editing. This is because, it is not possible to have the consent of the future generations that will be impacted by it. However, all decisions in the matter of gene editing including whether somatic cell gene editing or germline gene editing that should be allowed are invariably decided by 'ethics committees' in place at different levels—country-wise as well as globally.

Surely, everything that is possible in gene editing and other medical practices may not be permitted. For this, the 'ethics committees' come out with guidelines occasionally to check such abuse or misuse. In line with this, in its news release in 2021, WHO issued new recommendations on human genome editing for the advancement of public health to help establish human genome editing as a tool for public health, with an emphasis on safety, effectiveness and ethics (WHO, 2021). However, the fact is, only those who have a sense of collective responsibility will abide by such rules and regulations. There will be no way to keep track of every research laboratory to check abuse. There are high chances that things could go haywire anytime. In fact, nothing is and can be fool proof, for example, even with all the laws and legislation in place, even crimes of the highest orders are still rampant. However, that should not deter us from taking more stringent measures when it comes to gene editing. We can learn from such experiences and be extra cautious when it comes to ethics related to gene editing. A more nuanced approach needs to be adopted in the teaching-learning

[4]Eugenics is the selection of desired heritable characteristics in order to improve future generations, typically in reference to humans. https://www.britannica.com/science/eugenics-genetics (Accessed on 4 December 2024)

process. While crimes—heinous or not, are not acceptable at any cost, crimes such as murders end with it. There is nothing inherited. However, the result of gene editing in the germline will be observed for 'eternity', generations after generations. Whether that is good or bad is a different question but students need to be made aware about such long-term effects and this will happen only when it is discussed in the classroom. However, just as it is with criminals, it is up to the students what they want to do with their understanding about matters related to ethics. But the argument being made here is not that we should stop all innovations just because there will be somebody violating and misusing it somewhere. Rather, the argument is that there needs to be more pointed and serious discussions and deliberations in the classroom on matters as critical as this to society and humanity.

The above discussed aspects of equity, purpose, limits and boundaries, and exclusion of stakeholders equally apply to all technological inventions and innovations including the much talked-about artificial intelligence.

The Questions Beyond Ethics of Gene Editing

As mentioned earlier, the questions beyond ethics of gene editing include bigger and philosophical concerns that need to be addressed, such as our ultimate goal for the innovations and inventions. If, for some reason, some day, the world decides to remove all restrictions whatsoever related to gene editing, how will we react to that? Are we going to be okay with it? Are we going to try to now look for ways to live forever? Should we even attempt to do that? Should that solve human problem—our pursuit for contentment and happiness? What do we want to achieve for humanity through our knowledge of gene editing? Will there be an end to our quest and curiosity in our attempt to fix our health? Where should innovations and inventions not interfere in our body? Which features or characteristics of humans should we leave sacred? (Shimray, 2017) Is there any specific humanness that we think should not be desecrated or fixed and should be left untouched? How do we even decide? And who will decide that? Is it going to be the science community alone who should decide? Those are very pertinent questions for humanity to ponder about, especially for scientists who are going to make them happen in the laboratories.

Do our students have any clue that there are questions as mentioned above that they need to think about? Do we want our students and researchers to just go with the flow? Those are the bigger questions that we should have answers to—questions not just about ethics but beyond them. We might want to have clarity on the 'why' every time we want to apply gene editing. We fall short of discussing those aspects in our classroom, let alone finding answers to where we want to reach ultimately as *Homo sapiens sapiens*. Some day we would have been successful in manufacturing perfect population of people, but we would still find that the perfect people are fighting with each other for dominion and power. We will then realise removing physical pain and suffering due to diseases is not the ultimate solution, after all. As much as curing diseases can reduce human suffering, having a strong societal support system in terms of care, concern, compassion, etc., will be

equally important, if not more. Therefore, a healthy society cannot be achieved with just in terms of physical health but only with overall well-being—physical, mental and social.

From the above dicussions, we can arrive at the following points:

1. For technological inventions and innovations, such as gene editing to be truly beneficial to humanity, it is inevitable to understand the questions associated with ethics and beyond ethics.
2. Science classrooms should not shy away from considering questions related to ethics and beyond ethics when it comes to technological inventions and innovations.
3. However good technological inventions and innovations could be, or however good our intentions could be, we will not be able to achieve the overall well-being unless we look at human problems from all angles and not just by trying to alleviate physical suffering.

Suggestions for Science Education

How should we then steer the kind of education that we provide so that students are engaged in discussions about the bigger questions? Here are a few points that we might want to consider:

1. Curriculum developers may consider including such bigger questions so that adequate space and time can be dedicated to discussing them in the classroom. The prospects and possibilities to discuss about the bigger questions has opened up windows of opportunities in India with the latest National Education Policy 2020 highlighting the need to nurture students to make ethical decisions (MHRD, 2020, p. 16) and the recently introduced National Curriculum Framework for School Education 2023, recommending the introduction of a subject 'Individuals in Society' in Grade 9, in which 'identification of ethical and moral questions—whether there is violation of basic human values ...' (NCERT, 2023a, p. 399) will be part of the course. This is an excellent opportunity for curriculum developers for this subject to ensure the introduction of bigger questions through textbook and teacher training resources.
2. Not to suggest that they should be taught as a content in science curriculum but aspects which are beyond the science content such as, 'to be humane', 'what it is to be a human', 'what is equitable', 'how to achieve holistic well-being', 'what nature or aspect of human being should be left unexploited', 'are some lives more valuable than others', 'the philosophy of *Vasudhaiva Kutumbakam'*, etc., need to be the larger goal that guides the teaching-learning process in science classroom.
3. Curriculum for biotechnology and allied disciplines, which are application-oriented need to be guided by the bigger questions. For example, what is our ultimate goal of gene editing, or any effort in healthcare sector for that matter?

4. An introductory chapter of the curriculum may be dedicated to discussing this aspect, where students are engaged in critical thinking, debates and discussions, sharing their views. Understanding each other's views can shape students' understanding and opinion about the bigger questions.
5. Professional development courses and programmes—in-service and pre-service need to incorporate aspects related to ethics and beyond ethics so that teachers are cognisant about the bigger questions and make deliberate efforts to infuse them in the teaching-learning process, not only while teaching gene editing related topics but wherever possible.

Conclusion

The question about the bigger questions is not restricted to the big questions about the future of humanity and the big people in higher education institutions. Think of the Grade IV, V or VI students who are now developing apps! They have no idea why they are even doing except that it is cool. If they are big enough mentally and intellectually to develop an app, don't we think they are capable of thinking about the bigger questions suitable for their age? They surely are! All they need is to be introduced to such philosophy appropriately. That will go a long way in every walk of their life as they embark on different tasks or take up different responsibilities as part of their professions or other engagements.

Last, but not the least, coming back to our context of gene editing, beyond its role to prevent, treat and cure diseases, it is important to introduce the bigger questions related to ethics and beyond ethics in our curriculum as discussed in the article. Only when such fundamental questions are critically discussed in science classrooms, it is likely to guide or direct how we do science and thereby, our research and innovations. Otherwise, technological inventions and innovations will neither be accessible, available, affordable to all nor will have any ultimate goal without any limit or boundary and will be decided by the researcher's personal aspirations and not for the common good. It is also indisputable that technological inventions and innovations alone cannot address the issues facing humanity. Alleviating physical pain alone using gene editing technology to cure diseases will not bring about human well-being. There is a need for a holistic approach and for that, addressing questions related to ethics and beyond the ethics of technological inventions and innovations becomes imperative.

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