Gene editing and disabled people: a response to Felicity Boardman

Abstract

Is the germline gene editing (GEE) of embryos with disabling conditions a moral obligation? According to a recent editorial by F. Broadmann, there are strong reasons to hold the opposite, since " such a focus on the benefit to individual embryos is to overlook the broader societal changes that genome editing will signal, as well as the potential negative impacts on existing persons with genetic conditions". This paper is aimed at rebuking these arguments by invoking the human dignity principle.

Is the germline gene editing (GEE) of embryos with disabling conditions ethically acceptable or even a moral obligation, as Savulescu or Singer (Savulescu et al., 2015; Savulescu and Singer 2019), respectively, have argued? This challenging issue was addressed in the editorial authored by Felicity Boardman (Boardmann 2019). According to her, we cannot provide a fair general answer to this question without considering the opinions of people who suffer from these conditions and thinking about the consequences that such policies would have. This paper aims to rebuke her argument, stating that we are indeed obligated to use genome editing as soon as it determined to be safe enough to guarantee that its use will not cause harm to the affected offspring.

However, first, a point in which the author is undoubtedly right should be highlighted: unlike preimplantation genetic diagnosis (PGD), GEE does not send the message that not living at all is preferable to living with a concrete genetic trait that determines a concrete condition because the use of PGD tools results in the unavoidable process of destroying embryos with traits that will trigger concrete pathologies (Ranisch 2019). In contrast, GGE does not result in the destruction of embryos, but instead alters the expression of such traits, to avoid disease occurrence. This process creates a totally different scenario, resulting in this intervention sending an alternative and totally different message: that living without the condition is better than living with it, which appears to be an acceptable conclusion for everyone. Thus, GGE appears to be a perfectly acceptable and necessary method for addressing the issues posed by disabling genetic diseases when identified in *in vitro* embryos. However, Felicity Boardman challenged this conclusion by appealing to two different arguments: 1) the need to consider that at least some concrete conditions do not necessarily result in harmful lives and, thus, should not be eradicated; and 2) the relevance of the "expressivist objection" (Buchanan 1996), an argument that has been used to oppose embryo selection and may be used to oppose GGE (Parens and Asch 2003). Let us analyse these arguments.

The first argument is based on the idea that some of conditions that could be treated by the GGE of embryos are not necessarily pathological, or at least, that people suffering from these diseases are not looking forward to being cured. The author states

> a recognition of the emerging literature that explores the role of impairment experiences and identity politics, therefore, is critical to understanding the broad spectrum of responses that are currently being observed amongst genetically disabled people to technologies that ameliorate genetic disability, of which genome editing is but one.

I have some doubts regarding the accuracy of these statements. I doubt that they serve to prove that, in general, living with a disability might be better than (or at least similar to) living without a disability. I do accept that some patients (which I will refer to as A-type patients) might be reluctant to accept therapy. However, determining how representative these patients are of the collective population can be difficult. We should give extra weight to the opinions of those patients who have not suffered from conditions since childhood because they are the only ones who can make comparisons between life with and without these conditions. Unfortunately, many genetic diseases have very early onsets. Therefore, gather this type of information can be difficult. Under these circumstances, I conclude that we cannot make definitive conclusions regarding the issue at stake.

This preliminary conclusion appears to be particularly relevant given that the author herself recognises that the views held by adults with genetic disabilities towards screening and testing vary and can be contradictory (Taneja et al. 2004; Boardman et al. 2016; Barter et al. 2016), indicating that some patients look forward to supporting GGE. This group of patients (which I will refer to as B-type patients) may consider that their lives would improve upon the removal of suffering from a concrete condition. Therefore, I must ask how we can determine whether an embryo with a concrete condition will become an A-type or a B-type patient? Answering this question is impossible, in my opinion. If we decide not to use gene editing two outcomes are possible: he or she thanks us for choosing not to use gene editing because he or she appreciates living with that condition or the opposite could occur, and he or she would have preferred not to suffer from the concrete condition. In such circumstances, what decision should be made? To solve this dilemma, it is necessary to stress that if we intervene and the person does not suffer from a concrete condition (such as spinal muscular atrophy, for instance) he or she is unlikely to missing anything. Thus, we are faced with a scenario in which three out of four possible results indicate the morality of the intervention, according to the embryo's interests. Therefore, we have a nice argument that supports the gene-editing of human embryos; because we are in doubt regarding whether an embryo would prefer to suffer from a disability, we must act in a way that is less likely to contravene its will. This criterion definitely supports GGE. Thus, we must conclude that Broadman's first argument in support of refusing this tool is quite feeble.

Let us focus now on her second argument, which is that we should not alter only some types of pathological conditions in embryos because such a list could worsen the situation for those people who already suffer from these conditions (Coller 2019). This

belief is quite common and has been previously reported in the academic literature (Soniewicka 2015). Indeed, several papers have highlighted that using GGE to prevent new children from suffering from some concrete conditions could provoke changes in the public profiles of those conditions, causing emotional harm to those who suffer from conditions that the wider society prefers to avoid (Boardman 2014, Barter et al. 2016) and reducing the availability of community support (Nuffield Council on Bioethics 2018; Boardman et al. 2018). This second argument is somehow reinforced by a third argument, which is grounded in societal interest, that "the majority of people with genetic disabilities feel that it would be a loss to society to have fewer people with their particular condition coming into the world" (Boardman and Hale 2018).

In my opinion, this final assessment is not consistent. Whether our societies would be better without people suffering from certain conditions can be difficult to assess because there are currently no methods for preventing these conditions. However, I dare to think that we are unlikely to suffer from the eradication of haemophilia, for instance. However, I would prefer to base my refutation on the idea that even if forcing people to suffer from concrete conditions would be better for society, we should not make decisions based on this criterion. The only applicable principle for medical decisions should be the interest and welfare of the affected person. If not having a condition is in the interest of an affected person, the interests of the rest of the society should not be allowed to override that interest. Otherwise, we would be violating human dignity, treating unique human beings as mere means instead of as ends.

The same objection could be made to the second claim made by the author; even though the progressive loss of a condition could cause harm to those people already suffering from that condition, this situation should not be used to avoid the use of GGE that can prevent the condition in future people. If we proceed the other way around, we would be stating that the interest and welfare of human beings must be sacrificed for the good of the collective. In my opinion, this belief that could guide us down a dark hole, which could be used to argue that social eugenics are justifiable (Savulescu, 2002). Of course, I do not consider discrimination against disabled people to ever be justified or that funding devoted to addressing such situations should decrease. We should fight against suffering with all available resources. However, creating more disabled people should never a method for addressing existing suffering if we are to respect human dignity.

My conclusion that Felicity Boardman's editorial includes some extremely interesting thoughts. Indeed, we must hear the voices of people affected by different conditions (Boardman and Hale 2018) provide them with all possible means for living their best possible lives, and we must pay attention to their statements to identify which conditions are pathological which conditions should not be labelled pathological. However, we should not sacrifice the interest those who cannot express their opinions because they have not yet been born, which would undermine human dignity, which is a principle that we would all choose to preserve as an unbreakable barrier. Instead, if we respect the human dignity principle, we should edit their genome (De Miguel 2018; Raposo 2019).

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