

DOES IGNORANCE SHELTER US FROM MORALLY-CHALLENGING SITUATIONS?

We predict a future where medicine will be based on prevention, instead of treatment, as we discover the means to do so through genome sequencing. However, the continuous advances in the field of genetics are raising many ethical concerns. Questions like what it means to be human, what should be preserved or improved and whether eradication of disease and disability alleviates human suffering, are becoming increasingly topical and sparking criticism in public opinion. The controversial field of genetic screening is slowly settling into our reality as techniques and accuracy improve, but at what cost?

To explore this, I developed the following research question: "*does ignorance shelter us from morally-challenging situations?*". Aiming to discuss when not knowing will protect us from ethically ambiguous situations, it was also formulated to explore an area that is both morally challenging as well as controversial in the media and society. This represents an added pressure and actually enhances the protective value of this unknown.

The piece I developed represents an adaptation of the Schrodinger's cat paradox (1). Although this was originally used to interpret quantum physics, it shares a crucial principle with this research question: an unknown state. In the original experiment, a cat, hammer, Geiger and radioactive substance were placed in a box. When the radioactive substance decays, the Geiger detects it, triggers the hammer, releases the poison and subsequently kills the cat.

However, radioactive decay is a random process, hence, until the box is opened, it is unknown whether the cat is alive or dead. Inspired by this, the piece is composed of a box, containing various embryos. These, until screened, can both be either healthy or not. The process of screening is equivalent to the opening of the box, so what was unknown becomes known. Its purpose is to question if opening the box and knowing the fate of the embryos is best, or whether it results in having to make more difficult decisions. It also aims to investigate what makes someone want to take the responsibility of this action when it can be easier to stay ignorant. As such, it encloses theories of ethics, politics and social science through its design and the arguments it raises. The cube represents a choice, and an activity on its own, meant to be carried out whilst reading this piece. By doing so, those interacting with the activity will understand how it was constructed and will be able to interpret and understand its purpose from various perspectives with relation to different contexts.

The box is white, with minimal design to mimic the sterile environment of a hospital. Its surface is a collage of newspaper articles, representing the pressures by media and society on individuals, where some crucial headlines highlight judgement and bias by both pro and against parties, increasing the difficulty of this decision. On the front, it reads 'Open to Screen DNA'. This action is symbolic as it will reveal the state of the embryos and result in a positive (green) or negative (red) outcome. It indicates where one stands with regards to the research question: opening to choose to know what it contains and potentially facing morally-challenging situations or leaving it closed believing ignorance is bliss. It represents the choice any parent has or will have to make.

Therefore, its audience involves a portion of the general public who plan on starting a family (young adults) and teenagers who will want a child in the future, as the advances in the field are already being implemented in our reality, changing how our society thinks, and suggesting these decisions will become the norm in the future.

These elements work together to convey that fear and repression aren't towards screening itself but towards the results. It is these that will determine the responsibilities of the parents, resulting in the need to make incredibly difficult decisions. It is, in fact, debatable that parents may not want to open the box so that they don't have a choice, relieving them of the responsibility of their child's life. The same way, for example, an expecting couple may choose to avoid traveling to a Zika-infected country, as this will make them responsible for their future child's illness. However, screening will provide parents with a definitive answer and a new set of obligations they will need to meet to provide a good life for the child. If these can't be met, parents may choose to abort the child for what can be argued to be 'selfish' reasons and will blame themselves. Aiming to act in the best interest of the child involves taking into account many conditions. For example, the misconception of disability in today's society represent an additional difficulty for parents (2). This is a very topical subject at the moment, as advances in screening threaten minorities who believe their conditions have not debilitated them. As we discover new ways to beat natural selection, can science and politics replace this? Can the implementation of screening be considered a new form of natural selection? Who are we and what gives us the right to decide this? Fear of repression, judgement and discrimination from society can therefore bring parents to abort their child as well as additional challenges like financial stability, access to healthcare and age.

While the concept of blame may push individuals away from screening, it can also bring parents to screen. It can be argued that carriers of life-limiting conditions, like cystic fibrosis, owe it to their child to screen them and find out whether they will have the illness (3). This is a crucial area of genetic inherited diseases where parents, as carriers, have direct effect on the life of their child. As carriers, they may know how debilitating the condition is and will have to question whether they will want the child to go through this (4). This raises questions like what is a good life, and can they provide this? Will the child suffer living with this condition? It also introduces religion to the discussion, as believes may take away parents' choice with regards to this matter.

As discussed, opening the box confronts parents with the ethical decision of aborting or not based on what is in the best interest of the child and how they provide for them. However, can keeping the box closed actually bring more responsibilities to face? From a social aspect, not screening means parents have to prepared to face the eventuality of diversity of their child, taking into account to what extent this diversity will be accepted in a society where bullying and intolerance still prevail. The financial aspect may pose a challenge as to whether parents can afford to care for their child with respect to healthcare and supportive services throughout their life. This, however, does depend on the gravity of the case. Finally, the chance of a terminal illness, like in the recent case of Charlie Gard (5), will require the parents to decide the fate of their child and how far treatment should go before it is not in his best interest.

In conclusion, the piece aims to spark conversation on this topic, without compromising one's right to open the box. It focuses on the nature of this decision being a choice that everyone should be able to make based on their beliefs. It aims to make its audience question why they have made their decision, while taking into account its many possible aspects. There is no definite answer to the research question "*does ignorance shelter us from morally-challenging situations?*", however the consequences of choosing to screen or not to should always take into account what is in the best interest of the child.

WORD COUNT: 1388

References:

1. "The Physics Behind Schrödinger's Cat Paradox." *National Geographic*, National Geographic Society, 14 Aug. 2013, news.nationalgeographic.com/news/2013/08/130812-physics-schrodinger-erwin-google-doodle-cat-paradox-science/.
2. Parker, M. "The Best Possible Child." *Journal of Medical Ethics*, U.S. National Library of Medicine, May 2007, www.ncbi.nlm.nih.gov/pubmed/17470505.
3. Savulescu, J, and G Kahane. "The Moral Obligation to Create Children with the Best Chance of the Best Life." *Bioethics*, U.S. National Library of Medicine, June 2009, www.ncbi.nlm.nih.gov/pubmed/19076124.
4. Savulescu, J. "Procreative Beneficence: Why We Should Select the Best Children." *Bioethics*, U.S. National Library of Medicine, Oct. 2001, www.ncbi.nlm.nih.gov/pubmed/12058767.
5. "Charlie Gard: The Story of His Parents' Legal Fight." *BBC News*, BBC, 27 July 2017, www.bbc.co.uk/news/health-40554462.