

Student Devised Assessment – video

Summary

The video narrates a story in poem form about the success and limitations of genetic research. There are many subtle elements inspired from the workshops, for example, the ethical implications of aborting an embryo due to inherited genetic illness (week 4), the legal ability to do so and subsequent emotional impact to the mother (week 5), as well as hinting towards a discriminatory response to genetic illness, despite developments in cellular technologies (week 2). This is all achieved with a constant spiritual theme, through the personification of 'Death' as well as my own perspective from studying an economics degree. The beauty of poetry means that the individual message can be unique to the reader/listener (Green, 2016).

The poem is narrated as the viewer watches the creation of an abstract art piece that links to the ideas and emotions presented. The black and white nature of the art symbolises the difficulties when analysing all the various viewpoints. Instead the viewer is forced to look at the problem from a narrow perspective. This is often evidenced in modern society, with the endless combinations including: science and ethics, or science and economics, politics and science and more (Condit, 2001). The individual watcher will have a unique take on the poem, depending on their own respective background and beliefs.

The issues presented by the poem become more difficult to assess from narrow perspectives and as a viewer, there is a desire to know more about the situation. Changing from black & white to colour indicates that there is a lot more left unsaid. The speed of the transition is rapid, to signify in the time it took for multiple perspectives to be analysed, a life has already been lost. There is no obvious time setting to the poem, to suggest that it could easily be applied to a genetic illness 50 years ago, one today, or in 50 years' time. The abstract nature of the art allows for multiple interpretations of each stage. The poem does not directly state who to blame, but the intention is to leave the viewer questioning why this outcome as occurred and what steps should be taken to prevent it from occurring again.

Purpose & Audience

There is no explicit solution presented by the poem. It would be too simplistic to suggest to increase funding into more genetic illnesses, as the viewpoint is limited to the narrator. As an economics student, I understand the difficulties when incentivising research into cures for rare illnesses. In a profit-seeking society, patents are in danger of placing a price on healthcare and in some cases, a human life. The US alone holds over 45% of the global pharmaceutical industry, valued at 446 billion USD (Statista, 2018). With over 10,000 different types of monogenic disease* (WHO, 2018), research will be limited to those with a greater need & understanding.

However, the time context is extremely important and one which was intentionally left ambiguous. Mentioning that the discrimination is due to the unborn baby's genetics suggests that this is a world where the demand for a cure motivates the funding and research into the cure. Though developments such as CRISPR/Cas-9 are revolutionary, as time progresses,

other diseases and mutations will arise that will be difficult to understand despite the advancements in cellular technology. The slippery slope argument is alluded to as research is focused to a select population with a certain genetic makeup. Mutations that are rare would be unlikely to see a cure.

The intended audience for this video is everyone, regardless of their background, religion, gender, political beliefs as it spotlights an ongoing issue that is feared to deepen as cellular technologies improve. It is often too easy to blame doctors for their inability to provide a solution in the example of the poem, however this would be analysing the issue from a black & white perspective.

The issue lies with legislation, lack of funding, inability to support both mother and child, all of which involves many other players. My research surrounding the BEINGS summit uncovered many ethical grey areas, such as the debate surrounding the 14-day rule and global consensus on human cellular biotechnological legislation (Wolpe et al., 2017)

Form & Motivation

I enjoy creative writing, especially when creating a narrative about overcoming an emotional difficulty. Poetry allows for multiple interpretations, which was extremely important for the themes and perspectives highlighted. I wanted this poem to be a narrative that anyone could understand, regardless of their spiritual/religious beliefs. Death in this case, can be viewed as a spiritual entity that would resonate with many religious beliefs (Mermann, 1992). It could also represent the severity of the genetic illness which is again a clear theme throughout the poem.

Despite initial positive reaction to the written poem, I always knew I wanted the poem to be narrated. This links to the motivation behind choosing this particular theme. From the age of twelve, I have been in and out of hospital suffering from Lupus SLE¹. At the time of my diagnosis, I have a distinct memory of the doctors telling me how lucky I was, despite the swelling in my joints preventing me from walking and going to school. This is due to the lack of understanding of the illness and 10-15 years ago, sufferers tended to be misdiagnosed with ineffective treatment and often shortened life expectancy. In comparison, last year I had a second round of a recently developed immunotherapy** which has meant I could continue with university studies with reduced risk of a flare. As well as this, developments in medications has allowed for better management, enabling me to live a relatively 'normal' life. Though the causes behind the illness are still not entirely understood, researchers believe there to be a combination of genetic and external factors.

Hence by narrating the poem, I hoped to convey the emotion by channelling my own experiences and fears when looking to the future. Inspired by the use of colour to create a certain mood from watching GATTACA and the subsequent workshop (Week 2), I wanted to

¹ Lupus SLE: an autoimmune disease that effects skin, joints and can also involve organs (Arthritis Research UK 2018).

infuse this with the spoken poem. Watching YouTube videos of abstract art, further cemented my desire to incorporate this, especially due to the differences in opinions as to what the piece represents. My motivation to create a video was enhanced with research into synaesthesia, a condition where people neurological pathways for sensory inputs connect in different manners to normal physiology. Often people who are born with synaesthesia, experience emotions and thought through different neurological pathways (Banissy et al., 2014). For example, when perceiving emotions some may experience smell, touch or colour. Throughout history, colour has been used as forms of therapy, known as chromo-therapy (Samina, 2005). Because of my research I wanted to utilise some of the interesting science around colour as part of my piece. The artist I was particularly motivated by Jeremy Sicile-Kira, an artist who is autistic and expresses emotions through art in basic colours, I chose to stick to 5 colours – black, white, red, yellow and blue (People, 2016).

Although screening is not mandatory in the UK, the NHS carried out 21 million screening tests for all conditions between 2015-16. Furthermore, in 2016, the BBC reported an article stating 90% of mothers who know their child will be born with Down Syndrome have an abortion.

As someone with a relatively unknown illness, it's likely that I will be pressured to submit to prenatal testing to ensure the child will live a 'good life' as suggested by Boardman (2011). As genetic technologies develop further, the global consensus becomes increasingly more ambiguous. Without clearly established institutions, especially in regards to legislation and rights, a pregnant mother could be pressurised to abort without knowing all their options.

Furthermore, discussing perception and understanding of Down Syndrome with mothers in Week 9, highlighted the lack of information and awareness of legal rights. There is an increasingly vocal protest for 'disable' individuals to be included in debates about developments in genetic screening and research. This further highlights the issue with a limited perspective (as portrayed through the first portion of the video).

Concluding remarks

The video's primal aim is to spark an emotive response, whether that be anger, sympathy, fear and more. Though individual beliefs about Death, fate, religion may differ, we are united in our emotions, both in similarities but perhaps more importantly, differences. Genetic screening, and the debate surrounding termination has been a polarising issue for decades, through completing this SDA it was clear that by having open conversation about different emotions that are held, in a respectful and understanding manner, can effective change occur.

Word Count: 1,456

Bibliography

Music used in the video:

<https://www.youtube.com/watch?v=GEEisg9EV10>

An instrumental, orchestral remix of: Coldplay O “Fly On”

<https://www.youtube.com/watch?v=Ap-HeMIKi-c>

The music choice was extremely important as I did not want something too sad, or overpowering. At the same time, it needed to accompany the various emotions in the poem. This song talks of lost loved ones; however, it is focused on the fact eventually they will be reunited.

Artists used for inspiration:

- **Rikka Ayasaki**

<https://assets.saatchiart.com/saatchi/6134/art/3991722/3061576-LDJGBKRF-7.jpg>

- **Jeremy Sicile-Kira**

<https://www.jeremysvision.com/>

- **SurajFineArts**

<https://www.youtube.com/channel/UC0DAJW9IjtV4Ilz7dDVDBFA>

These artists served as the main sources of inspiration for the art piece I created as part of the video. In particular, their techniques and styles to express emotion were of notable quality. I practiced the techniques using Suraj Fine Arts’ videos of creating the abstract pieces using pallet knife and acrylic paint.

Synaesthesia + using colour

Palmer, S. 2014. "Colour, Music, and Emotion in Synesthetes and Non-Synesthetes". *YouTube*. [online] Available at: <https://www.youtube.com/watch?v=iGDF7TT7yBE> [Accessed: 4th April 2018].

Palmer, S 2011. Colour, Music and Emotion. *Journal of Vision*, 11(11), pp.91-391.

Both the video and article helped me understand how colour can be used to represent emotions. It was important for me to study the theory behind it so that I could effectively implement it in the art piece.

Colour Psychology. 2018. The Psychology and Meaning of Color. [online] Available at: <https://www.colorpsychology.org/> [Accessed: 4th April 2018].

VeryWellMind. 2018. The Colour Psychology of Black. [online] Available at: <https://www.verywellmind.com/the-color-psychology-of-black-2795814>

Ancient Egypt Online: <http://ancientegyptonline.co.uk/colour.html>

These articles helped formulate the different meanings behind each colour in the piece and the reasons why I chose to use them in a specific order. I kept the range of colours limited to that used in Ancient Egypt, where colour was used as a form of medicinal therapy.

Supplementary Research

Down's Syndrome Association: <https://www.downs-syndrome.org.uk/>

Melissa Conrad Stöppler, MD. Genetic Diseases - Types, Symptoms, Causes, Definitions: https://www.medicinenet.com/genetic_disease/article.htm#what_is_a_genetic_disease_how_is_it_defined

The research here enabled me to see which types of genetic mutations are currently the most difficult to treat. Although the poem focuses on my own experiences with Lupus SLE, I wanted to ensure that it could be applied for other genetic illnesses too.

Kathleen Connolly Baker. Nicholas Mazza. 2007. The healing power of writing: applying the expressive/creative component of poetry therapy. *The Interdisciplinary Journal of Practice, Theory, Research and Education*, 17(3).

I found this research paper interesting especially since they were studying the effects of therapeutic writing for a client with Lupus. This cemented my desire to create a written piece for the SDA.

References

Arthritis Research UK. 2018. Lupus SLE [online]. Available at: <https://www.arthritisresearchuk.org/arthritis-information/conditions/lupus.aspx> [Accessed: 15th April 2018].

Boardman, F. 2011. 'Negotiating Discourses of Maternal Responsibility, Disability and Reprogenetics' *New York: Syracuse University Press*, pp.34 – 49.

BBC News. 2016. A World Without Down's Syndrome? [online] Available at: <http://www.bbc.co.uk/news/magazine-37500189> [Accessed: 16th April 2018].

Condit, C. 2001. What is 'public opinion' about genetics? *Nature Reviews Genetics*, 2, pp.811–815.

Green, A. 2016. Actual Texts, Possible Meanings: The Uses of Poetry and the Subjunctification of Experience. *Studies in Culture and Education*, 23(4), pp. 351-362. <https://doi.org/10.1080/1358684X.2016.1203247>

Mermann, A. C. 1992. Spiritual aspects of death and dying. *Yale J Biology Medicine*, 65(2), pp.137–142.

Banissy M. J., Jonas. C. and Kadosh C. R. 2014. Synaesthesia: An Introduction. *Front Psychol.* 5(1414).

NHS England. 2016. Screening programs in England. [online] Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/574713/Screening_in_England_2015_to_2016.pdf [Accessed: 16th April 2018].

People. 2016. California Artist with Autism Uses His Synesthesia to Paint Vivid Portraits: 'I See Beautiful Colors in My Dreams' [online] Available at: <http://people.com/celebrity/artist-with-autism-paints-portraits-using-synesthesia/> [Accessed: 16th April 2018].

Samina T. Yousuf, A, Mohsin, R. 2005. A Critical Analysis of Chromotherapy and Its Scientific Evolution. Evidence Based Complement *Alternate Medicine*, 2(4), pp.481–488.

Statista. 2016. U.S. Pharmaceutical Industry - Statistics & Facts. [online] Available at: <https://www.statista.com/topics/1719/pharmaceutical-industry/> [Accessed: 16th April 2018].

WHO. 2018. [online] Available at: <http://www.who.int/genomics/public/geneticdiseases/en/> [Accessed: 16th April 2018].

Wolpe, R. P., Rommerlfanger, S. K. and the Drafting and Reviewing Delegates of the BEINGS Working Group. 2017. Ethical Principles for the use of Human Cellular Biotechnologies. *Nature Biotechnology*, 35, pp.1050-1058.