Ripped Genes, And How To Wear Them:

Throughout this module, the many discussions and debates surrounding genetics have covered various issues, from ethical considerations of pre-natal testing, to the impact of genetic engineering on society. However, as someone from a psychological discipline, I felt that little reflection was given to the psychological impact of genetic testing on individuals and their unborn offspring. During my time working on this module, I was unaware of the current support networks available for people who had received, were undergoing, or would be requiring to receive genetic testing, as well as obtaining little knowledge about how such treatments are carried out, and if they sufficiently deal with life-changing decisions and results.

From this query, my attention was brought to genetic counselling. Genetic counselling assists people who are at risk of having, or passing an inheritable genetic disorder onto their future offspring by delivering a process in which they are provided with information of their genetic illness by trained professionals. This includes knowledge of the inheritance of genetic illnesses, its recurrence risks, and addressing concerns and supporting the patient and their family to adapt to the psychological, familial and physical deficits of the disorder (World Health Organisation, 2018). However, while this definition outlines what the basic processes involve, there was still no disclosure on the requirements one needs to see a genetic councillor, leaving a stale sense of ambiguity around the subject. After researching the topic, I discovered I was not alone in this sense of uncertainty, as the majority of the general public also lacked an understanding of what genetic counselling was, and what to expect from counselling sessions (Biesecker, 2001). Furthermore, informed parties formed mixed opinions about the process of genetic counselling, sharing criticism about the amount of influence genetic councillors have over patient decision making, difficulties establishing intended goals of counselling sessions and treatments (Biesecker, 2001), and whether councillors effectively reassure patients once they gain an understanding of the potential implications of receiving either positive or negative test results (Wiggins et al., 1992; Tibben et al., 1992)

While one could argue that genetic counselling is a process designed to help the individual, there is also a large amount of variation in the counselling procedure per hospital and practitioner (Motulsky, Holtzman, Fullarton, & Andrews, 1994) which may result in varied opinions and understandings of genetic counselling, as some may receive insufficient support when undergoing genetic testing. Because of this, my student devised assessment aimed to address the current issues surrounding genetic counselling, as well as settling pending questions on what genetic counselling entails, and who receives it. I wanted to focus on a general public audience, as I believe they have a right to be better informed about the support available to them, as well as having an awareness of the difficulties they may face during genetic testing. I also aspired to highlight current or proposed solutions to problems surrounding the current counselling regime to emphasise the transition of genetic counselling towards the goal of a patient-oriented approach (Motulsky, Holtzman, Fullarton, & Andrews, 1994).

As someone who takes great interest in contemporary science communication, I have decided to use a documentary-style medium to address the general public audience. Mass media platforms, such as social media have been found to give scientists control of their published content, but also allows for scientific entertainment and a two-way interaction between the scientist and the public regarding questions on this topic (Biswal, 2018). By

using a documentary medium, this further allows the general public to engage with scientific debates and research at a non-academic level which is informal, yet informative. My intention was to use my own voice as a narrative to critically engage with the various ethical and sociological topics tackled during the module, transcending and including several disciplines to highlight the extensive complexity of the complications faced by genetic counselling during its progression to becoming a patient-centred support network. Additionally, the narrative is partnered with visual aids of animation, infographics and various footage from familiar media and cinema which mirrors the issues addressed. I believe that this mode is the most suitable for my chosen topic for a multitude of reasons. It has firstly been found that using a multimedia approach is more effective towards learning due to its benefits in increasing memory and cognitive load (Brunken, Plass, & Leutner, 2003). Secondly, using media to popularise science in the public eye is becoming increasingly more common, with scholars like Carl Sagan making science more appealing to wider audiences (Olson, 2009). Finally, it gives the ability to construct a personalised account of information, tailored as if talking to an individual. This reflects the objective of personalised support for genetic counselling patients, to which the use of scientific jargon is one of the many factors which contribute to the confusion surrounding genetic disorders, their implications and treatments (Farrell, Deuster, Donovan, & Christopher, 2008).

My student devised assessment aimed to implicitly focus on the portrayal of genetics in cinema, and its influence over public opinion regarding genetic technology (Kirby, 2007). Much of genetic science function illustrates a futuristic, dystopian consequence of harvesting the power of genetic technology due to a lack of awareness of how to effectively control it. My piece includes the cinematography of *Frankenstein* (Whale & Laemmle, 1931) to highlight the public interpretation of genetic technology as a short leap from science fiction. Furthermore, the documentary also incorporates scenes from *My Sisters Keeper* (Furst et, al., 2009) to showcase ultramodern concerns about the impact genetic testing can have on family relations, including guilt, financial impacts and ostracism (Wiggins, et al., 1992; Tibben et al., 1992), as well as *GATTACA* (Devito, Shamberg, Sher, Lyon, & Niccol, 1997) to parallel the potential fears of discrimination which can arise from genome testing, such as an inability to obtain life insurance (Joly, Feze, & Simard, 2013). Additionally, the project uses my own home videos to emphasise the focus on the individual and those who surround them, as well as to tackle the adoption of guilt and blame many parents experience if their child has a genetic disorder, when in reality they are only passive victims of an indiscriminate genetic event (Wexler, 1992).

A large majority of my assessment further revolves around the slippery slope argument (Resnik, 1994). As arguably one of the largest debates in genetic science, many are apprehensive that the rise in genetic modification and the prevention of genetic diseases will result in such technologies to be pushed to and beyond the ethical boundaries due to an arguably eugenic attitude within genetic science (Resnik, 1994). This translates into counselling through difficulties disclosing potential treatment and prevention in a non-directive manner without influence of personal opinions regarding genetic disorders in the wider population (Motulsky, et, al., 1994). By regarding the views of medical professionals (Motulsky et, al., 1994), disabled activist groups (Biesecker, 2001), and those who have experienced genetic counselling (Hayes, 1992), I aimed to stimulate thought within the audience and provoke a more diverse consideration of various

opinions of those involved, which I have learnt to do from an interdisciplinary perspective.

While much of the information in my assessment derives from patients who receive genetic counselling, it also incorporates the problems individuals face who do not receive support once they have obtained results. Until tests are received, all patients undergo the same treatment, and experience similar concerns of anxiety, stress and doubt (Muthuswamy, 2011). However, those who obtain negative test results regarding a genetic disorder do not always receive equal support compared to those who tested positive, yet at the same time they find themselves on a foreign psychological landscape of survivor-guilt and isolated relationships between themselves and effected family members (Quaid, 1992). To address this concern, my documentary included accounts of real patients describing their psychological experience of genetic testing to emphasise the scale of impact their results can have on relationships with others and themselves (Hayes, 1992). This brings to light a more bespoke insight into genetic medicine beyond the traditional use of facts and figures. Also, my student devised assessment declares various commercial genome sequencing companies who do not disclose, in an appropriate manner, repercussions of genome testing, nor offer direct support for individuals who receive genetic information. This highlights the importance of the general publics need to understand the impact of genome sequencing before they undergo testing, commercialised or otherwise.

Following the conclusion of my piece, I wanted to deliver three topics for the audience to consider: firstly, I hope that the public audience obtains a comprehensive awareness of the current and potential processes of genetic counselling, as well as the benefits and difficulties faced by all involved; secondly, I hope to encourage the general public to reflect upon the various opinions and debates surrounding genetic counselling, in the same way as I have learnt to reflect on interdisciplinary issues addressed in this module; finally, I wanted to highlight potential solutions towards implementing a universal, non-directive procedure of genetic counselling. By enforcing a patient-centred approach to decision making, the patient can learn to gain a unique sense of power over the situation, rather than giving dominance to the disease itself. To guide this, the reliable support and consideration of a specialised genetic counsellor can progress to a psychological dynamic of acceptance and adjustment towards a condition one may feel to have no control over.

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