

SDA companion piece

Can be accessed at: <https://youtu.be/20uy-CBL-Zo>

The topic I chose to cover for my student devised assessment (SDA) is: *Genetics in the news: fake news and what you should believe*. It is a presentation/talk aimed particularly at women who are looking to have children or start a family, are worried about either passing on a genetic condition that runs in their family or the possibility that they and their partner carry recessive diseases without knowing. It's attempting to inform and educate about genetic testing in embryos, Preimplantation Genetic Diagnosis/Screening, whilst disproving 'false' or exaggerated reported about these technologies in the news.

In the talk, I touch upon what genetics are, what genetic diseases/disorders are, the role of PGD and PGS and the role of a genetic counsellor. It is a step-by-step talk on what they could expect to happen in a clinical/medical setting. I briefly talk about the idea of 'eugenics' and provide a small glimpse into the ethical debate (as the aim is to inform and reassure, not to create ethical discussion), followed by the actual realities of PGD. I then switch to the role that news outlets play in distributing information to the masses. I compare the 'same' news produced by different outlets to guide the mothers on what to believe and what not to believe when looking for news on these biotechnologies. I also include positive stories reported in the news and how it can act as a means to promote the benefits of these technologies as well. I want to leave the audience confident with what they should expect in this process, the benefits and risks of testing, PGD and PGS, and where to find support and accurate information in the news.

I chose this topic because there is an inherited heart condition within my family, and after seeing the pain it has caused and continues to cause, I personally would want to do anything in my power to stop it being passed on to a future baby. Whether that be by technologies such as PGD, or by another reproductive technology, I want to be educated about my potential options.

Inspirations

There were a few lectures on this course that particularly inspired me to choose this topic, alongside my personal family history. The first being Robert Old's lectures where he briefly touched upon the impact medical screening has on women/the role women play. The information on current prenatal fetal diagnosis techniques struck me as quite scary despite having a scientific background. He also quoted in within this lecture that 22,000 women undergo invasive testing in England annually, which again shocked me and led to the initial idea that women need support and information before they go through a process such as this.

The second lecture that inspired me to tackle creating an informative talk was Caroline Wright's, on reprobogenetics. It mentioned the huge, fundamental role women play and the side effects that come with it (feminist approach), linking in the new preimplantation genetics, which I believe will become more prominent in society due to the increase in age in which women now choose to get pregnant. Women are far more successful due to the vast increase in career opportunities compared to historical times and as a result many choose to have children later on in life. However, the later the pregnancy, the greater the risk of complication. Hence, this is why IVF is on the rise and why I believe PGD/PGS will increase too. During her follow-up workshop, we also considered the public's perceptions, which inspired me to look at the role the news plays in conveying information on genetics. The news is read by millions on a daily basis (as shown in the SDA) and can lead to misconceptions of what the role of genetic testing, screening and diagnosis actually is. The idea to look at the news was reaffirmed by David Kirby's lecture, where he stated that the best way to make the public think a certain way about science was to relate it to them and to make them care, which is why a personal, informative talk may be one of the most effective means of communication. He also discussed the large impact movies has on shaping public opinion, and this impact is also seen through the news due to its global outreach.

During Felicity Boardman's lecture we also were able to speak to mothers of children with Down's syndrome who agreed that the medical profession needed to do more to educate and support mothers, which is why I have decided to tackle this topic.

Aims

My fundamental aim was to put together a short talk for women who have a genetic disorder or a history of genetic disorders and want to have children without passing on the disorder, but do not know the basics of what is available and do not know what to trust in the news. It is a basic talk focused on the main areas of genetic testing, screening and diagnosis. It is supposed to be informative and unbiased, as ultimately I believe women have the choice to find out about their inheritable genetics. When they have a strong history of genetic disorders/diseases, I believe women (and their families/partners) need to know they have the choice and that there are options available to them. The news tends to focus on what is exciting and controversial, what sells. Certain outlets tend to focus on reporting negatives/ethical debates ('no news is good news') which can worry prospective mothers and families. I want to briefly educate them on how to read the news and what to take from certain articles.

When studying genetics, many people focus on tackling the 'huge' 'scary' ethical questions and either agreeing with or refuting the sci-fi dystopia/utopian theories. They commonly forget the emotional as well as physical effect it has on the women who bear the impact of these technologies.

Medium used

I chose this particular medium after watching Jennifer Doudna's TED talk (Doudna, 2015) a scientist educating her audiences about CRISPR but also the ethical implications and duties we have to acknowledge. This inspired me to create an impactful talk/presentation in the same way. Ideally, I would love to be able to host a big talk, or even a TED talk, on this issue and present it to my target audience (as stated above). This has been proved as an incredibly successful method of communication, in particular, as viewers are streaming TED talks at the rate of 2 million times per day (Gallo, 2015). I would also like the talk to be recorded and uploaded to YouTube so it can be accessed by anyone. I would also want it to be uploaded to or hyperlinked within the NHS page on reproductives/screening. It's an engaging way of communicating this issue. People also love to hear stories, and this form of media allows you to engage in that way. I wanted to combine spoken word and scientific images and facts to communicate my research. The presentation is also kept close to 18

minutes as 'the TED event organizers have found that 18 minutes is the ideal amount of time to have a substantive discussion without putting people to sleep' (Gallo, 2015). I chose to take a personal yet informative tone, to keep the audience engaged and to keep it light hearted.

Audience

During this module, I have discovered that as a biomedical science student I take some things for granted, like my understanding of genetics. As stated above my target audience is women who are looking to have children or start a family, but are worried about either passing on a genetic condition, a genetic condition that runs in their family or the possibility that they and their partner carry recessive diseases without knowing, but do not know what to trust in the news. In 2017, 3.58 billion people accessed the internet (Statista, 2018) which is now one of the main ways to distribute news. The internet can be a scary place when multiple news outlets are reporting 'scary' genetic stories, or on 'the rise of designer babies', especially the Daily Mail, who's biggest target audience is women. This is important when considering my target audience as it mirrors this. I want to ensure they understand the facts on genetic testing/diagnosis of embryos and how to interpret news sources.

How I conducted my research

I utilised news statistics from my 'Science communication' module, undertaken as part of my biomedical science degree. I used information from Caroline Wright's, David Kirby's and Felicity Boardman's lectures on women's role in reprogenetics, reproductive technology, the impact on mothers and how to actually communicate this. I engaged in a passionate conversation with two mothers who have children with Down's syndrome and called for better explanation and support from the medical/scientific community. I studied the HFEA website (human fertilisation and embryology authority) and NHS website extensively to help compile a suitable informative presentation. I also looked for news articles that had been reported by at least 2 separate outlets and how they compared to the original study. I used scientific papers to understand PGD and PGS more as well as using the U.S. National Library of Medicine and the National Human Genome Research Institute to understand more about genetic testing.

Word count: 1535 (excluding Harvard referencing)

Bibliography

Doudna, J. (2015). *How CRISPR lets us edit our DNA*. [online] Ted.com. Available at: https://www.ted.com/talks/jennifer_doudna_we_can_now_edit_our_dna_but_let_s_do_it_wisely [Accessed 9 Mar. 2018].

Gallo, C. (2015). *Forbes Welcome*. [online] Forbes.com. Available at: <https://www.forbes.com/sites/carminegallo/2015/03/17/why-our-brains-are-wired-to-love-ted-talks/#22139bd91322> [Accessed 17 Mar. 2018].

Statista. (2018). *Number of internet users worldwide 2005-2017 | Statista*. [online] Available at: <https://www.statista.com/statistics/273018/number-of-internet-users-worldwide/> [Accessed 16 Mar. 2018].

Slide 3:

- nhs.uk. (2016). *Genetics*. [online] Available at: <https://www.nhs.uk/conditions/genetics> [Accessed 6 Mar. 2018].

Slide 4:

- Science Museum (2018). *Why is studying genetics important?*. [online] Whoami.sciencemuseum.org.uk. Available at: <http://whoami.sciencemuseum.org.uk/whoami/findoutmore/yourgenes/howdogenesaffectyourhealth/whystudyinggeneticsimportant> [Accessed 3 Mar. 2018].

Slide 5:

- D.C. Wertz, J. F. (2003). *Review of Ethical Issues in Medical Genetics*. Geneva: Human Genetics Programme, Management of Noncommunicable Diseases, World Health Organization. http://www.who.int/genomics/publications/en/ethical_issuesin_medgenetics%20report.pdf
- Archibald, A. D. (2017). Reproductive genetic carrier screening for cystic fibrosis, fragile X syndrome, and spinal muscular atrophy in Australia: outcomes of 12,000 tests. *Genetics in Medicine*. Published online in Nature

Slide 6:

- D.C. Wertz, J. F. (2003). *Review of Ethical Issues in Medical Genetics*. Geneva: Human Genetics Programme, Management of Noncommunicable Diseases, World Health Organization. http://www.who.int/genomics/publications/en/ethical_issuesin_medgenetics%20report.pdf
- U.S. National Library of Medicine. (2018, March 13). *Your guide to understanding genetic conditions*. Retrieved from U.S. National Library of Medicine: <https://ghr.nlm.nih.gov/primer/testing/geneticstesting>

Slide 7:

- National Human Genome Research Institute . (2017). *Frequently Asked Questions About Genetic Testing*. Retrieved from National Human Genome Research Institute : <https://www.genome.gov/19516567/>

Slide 8:

- Bouffard C, Viville S, Knoppers BM. Genetic diagnosis of embryos: Clear explanation, not rhetoric, is needed. *CMAJ : Canadian Medical Association Journal*. 2009;181(6-7):387-391. doi:10.1503/cmaj.080658.

Slide 9:

- D.C. Wertz, J. F. (2003). *Review of Ethical Issues in Medical Genetics*. Geneva: Human Genetics Programme, Management of Noncommunicable Diseases, World Health Organization. http://www.who.int/genomics/publications/en/ethical_issuesin_medgenetics%20report.pdf

Slide 10:

- Human Fertilisation & Embryology Authority. (2018). *In vitro fertilisation (IVF)*. Retrieved from Human Fertilisation & Embryology Authority: <https://www.hfea.gov.uk/treatments/explore-all-treatments/in-vitro-fertilisation-ivf/>

Slide 11:

- New Hope Fertility Centre. (2018). *Genetic Testing*. Retrieved from New Hope Fertility Centre: <https://www.newhopefertility.com/genetic-testing/>
- Bouffard C, Viville S, Knoppers BM. Genetic diagnosis of embryos: Clear explanation, not rhetoric, is needed. *CMAJ : Canadian Medical Association Journal*. 2009;181(6-7):387-391. doi:10.1503/cmaj.080658.
- NHS England. (2014). *Clinical Commissioning Policy: Pre-implantation Genetic Diagnosis (PGD)*. NHS Constitution
- Stern, H. J. (2014). Preimplantation Genetic Diagnosis: Prenatal Testing for Embryos Finally Achieving Its Potential. *Journal of Clinical Medicine*, 3(1), 280-309.

Slide 12:

- Bouffard C, Viville S, Knoppers BM. Genetic diagnosis of embryos: Clear explanation, not rhetoric, is needed. *CMAJ : Canadian Medical Association Journal*. 2009;181(6-7):387-391. doi:10.1503/cmaj.080658.
- NHS England. (2014). *Clinical Commissioning Policy: Pre-implantation Genetic Diagnosis (PGD)*. NHS Constitution
- Stern, H. J. (2014). Preimplantation Genetic Diagnosis: Prenatal Testing for Embryos Finally Achieving Its Potential. *Journal of Clinical Medicine*, 3(1), 280-309.

Slide 13:

- Bouffard C, Viville S, Knoppers BM. Genetic diagnosis of embryos: Clear explanation, not rhetoric, is needed. *CMAJ : Canadian Medical Association Journal*. 2009;181(6-7):387-391. doi:10.1503/cmaj.080658.
- D.C. Wertz, J. F. (2003). *Review of Ethical Issues in Medical Genetics*. Geneva: Human Genetics Programme, Management of Noncommunicable Diseases, World Health

Organization.http://www.who.int/genomics/publications/en/ethical_issuesin_medgenetics%20report.pdf

Slide 14:

- The lecture by Dr Caroline Wright on reprobionics inspired this slide on the reality of PGD

Slide 15:

- Bouffard C, Viville S, Knoppers BM. Genetic diagnosis of embryos: Clear explanation, not rhetoric, is needed. *CMAJ : Canadian Medical Association Journal*. 2009;181(6-7):387-391. doi:10.1503/cmaj.080658.
- Lectures from the Science Communication Life Sciences module, given by Luke Walton inspired the News numbers/followings/facts

Slide 16:

- Gallagher, J. (2017). *Human embryos edited to stop disease*. [online] BBC News. Available at: <http://www.bbc.co.uk/news/health-40802147> [Accessed 10 Mar. 2018].
- Allen, V. (2017). *Designer baby research 'should be publicly funded', experts claim*. [online] Mail Online. Available at: <http://www.dailymail.co.uk/sciencetech/article-4757908/Designer-baby-research-publicly-funded.html> [Accessed 9 Mar. 2018].
- Cary funk, J. G. (2018). 2. *General news outlets are the most common science news source; most-seen stories highlight discoveries and "weird" findings*. Retrieved from Pew Research Centre Journalism & Media: <http://www.journalism.org/2017/09/20/general-news-outlets-are-the-most-common-science-news-source-most-seen-stories-highlight-discoveries-and-weird-findings/>

Slide 17:

- De Graff, M. (2017). *Designer baby breakthrough: Disease removed from embryo in world first*. [online] Mail Online. Available at: <http://www.dailymail.co.uk/health/article-4930078/Disease-removed-embryo-world-first.html> [Accessed 8 Mar. 2018].
- Sample, I. (2017). *'Chemical surgery' used to mend harmful mutations in human embryos*. [online] Theguardian.com. Available at: <https://www.theguardian.com/science/2017/sep/28/chemical-surgery-used-to-mend-harmful-mutations-in-human-embryos-base-editing> [Accessed 6 Mar. 2018].

Slide 18 & 19:

- Balloo, S. (2018). *World's first gene test baby saved from heart condition which devastated generations*. [online] Birmingham Live. Available at: <https://www.birminghammail.co.uk/news/midlands-news/worlds-first-gene-test-baby-14275461> [Accessed 8 Mar. 2018].
 - On PGD news story

Slide 20:

- Spera, R. (2018). *These genetic tests before babies are born can be life-changing*. [online] ABC13 Houston. Available at: <http://abc13.com/health/these-genetic-tests-before-babies-are-born-can-be-life-changing/3155067/> [Accessed 7 Mar. 2018].

Slide 22:

- Genetic Disorders UK. (2017). *Genetic Testing*. Retrieved from Genetic Disorders UK: <http://www.geneticdisordersuk.org/aboutgeneticdisorders/genetic-testing>
- NHS England. (2014). *Clinical Commissioning Policy: Pre-implantation Genetic Diagnosis (PGD)*. NHS Constitution

Slide 23:

- Genetic Disorders UK. (2017). *Genetic testing*. [online] Available at: <http://www.geneticdisordersuk.org/aboutgeneticdisorders/genetic-testing> [Accessed 6 Mar. 2018].

Slide 24:

- Genetic Disorders UK. (2017). *Genetic testing*. [online] Available at: <http://www.geneticdisordersuk.org/aboutgeneticdisorders/genetic-testing> [Accessed 6 Mar. 2018].

Slide 27:

- The Parliamentary Office of Science and Technology. (September 2013). *Pre-implantation Genetic Diagnosis. Number 445*.