Prompters to Life

presents

Story Meets Science:

Genetics in the Real World

It could be argued that, with the mapping of the human genome and the almost constant discoveries of the genetic components many diseases, the most important questions in healthcare in the next 50 years will be those dealing with the ethics and practical outworkings of widespread knowledge of personal genetics. While this undoubtedly will be beneficial when it comes to screening for and detection of disease, it is easy to envision scenarios which may hide troubling trends.

My Story

1) I am a mutant
2) My issue is a protein which my genes lack resulting in a weakness in my mismatch repair process … this results in tumours (cancer), particularly in my colon
3) I have had colorectal cancer twice, the second time resulting in the (almost) complete removal of my large intestine both for treatment and prevention
4) My mutation is hereditary and, on conception, each of my 3 children had a 50% chance of inheriting my genetic flaw: one of my kids has the same broken gene that I do.

At this point, I'll draw my family tree on the whiteboard and describe the inheritance.

What is my mutation? I lack a protein called MSH2 which is a MMR gene. This means that my body has a hard time repairing certain kinds of flaws that show up in my dividing cells. When these flaws persist and multiply, they eventually become cancer. Specifically, cancer in the large intestine and in women, the lining of their uterus. I, and people like me and my mother and my son have a high rate of cancer: 60-80% chance of colorectal and 40-60% chance of uterine.

Because the root cause of my problem cannot be fixed, I have to live with routine surveillance to detect cancer before it occurs or to detect it when it is in its early stages. There is no cure for what I have.

I bring an uncommon perspective to the question of genetics, society, and the polices that we have not yet created to determine how we will (ought?) to approach genetics. Because you are going to see some of the outworking of the new genetic revolution, it is important that you begin to formulate ideas about what to think about certain issues but, more importantly, that you get a framework of how to make these decisions and what your influences are.

Ethics:

Let's talk just a little about four sources of truth:

1) Emotion: this is how you feel about something. Eg., you are in a dark room, you cannot find the light switch, from the corner you hear a creak, heavy footsteps, and deep breathing. How do you feel? Is the feeling right or wrong?
2) Logic: these are the conclusions you reach about evidence based on premises and internally consistent arguments. Eg., your mother is supposed to meet you at 4:00 but it is 4:05 and she has not shown up. However, she is often late and today there is a parade which is travelling down the route she would normally take. Logic would lead you to think she has been delayed and not that she has forgotten about you or had a tragic circumstance which prevents her from getting to you
3) Science: postulates a theory, runs tests (preferably double-blind) to gather evidence, and then declares the theory to be true or false.
4) Faith: for many, the questions of ethics and answers fall back to a system of faith and religion. It is impossible and illogical to try to silence that voice. However, consideration must be made of the intent of the rules that are followed and consistency with the other three sources.

One of the things you should keep in mind when answering any questions about ethical behaviour is that of source of truth. It is important that you have as many sources as possible and that they do not conflict. As well, when discussing differing sides of an ethical dilemma, you should be sure to determine what the sources of the other arguments are and whether you are talking about apples and apples.

Eg., when talking about origins of matter and of life, if one person exclusively of the opinion of science and the other exclusively of the opinion of faith you can never expect to have reasonable discussions nor to come to mutually satisfying conclusions. In the end, it is irrelevant who is "right" if you are so unaware of, or entrenched in, your own position to not acknowledge its influence on your opinion or the validity of another, if only from a "feeling" position.

Discussion:

The discussion part of the workshop is the most important. The genetics portion is a review. The ethics portion is theory. What is important is that students be able to discuss these questions (some or all) in groups while acknowledging their feelings and biases and identifying which, of the four, sources of truth they are relying on most heavily while acknowledging the potential for others to be relying on different sources. It is important to note that all of these discussion topics have been implemented in various jurisdictions around the Western world.

The recommendation is as follows:

1) Divide the class up into randomized and even groups, trying to avoid having people who frequently interact with each other to be a part of the same discussion group
2) Give each group one or more of the discussion questions with a time limit for discussion. Have them discuss with an emphasis on collecting data and identifying their sources of truth. It is acceptable for the group and/or individuals to come to conclusions, however, when doing so to identify biases. For example, "We think that this practice is unethical. While permissible from a scientific perspective, from most of our religious world-views we deems this action to be unacceptable." As another example, "we think that from a scientific perspective this is possible, from a logic perspective it seems that a minority of individuals would bear the brunt of the effects of this practice and so we do not see this practice as acceptable."
3) Have groups report back on the decisions of the group and dissenting opinions where there was not a group consensus. While doing this have them identify the sources of truth that led them to their conclusions.

The more time there is for discussion the better there is. This could easily take two class periods to discuss and debrief on.

Discussion #1: 23andMe.com

23andme.com is a company which will take a DNA sample and provide you with a breakdown of all of your genetic predispositions, privately and through the mail. You have a friend who is concerned that she might have a terrible genetic malady which her doctor refuses to acknowledge. What factors do you think come into play when considering using a service like 23andme?

Discussion #2: In Vitro Testing

You have a genetic mutation which is almost always (90%) fatal in its carriers by the age of 45. This mutation is passed on to children by a carrier 50% of the time. You and your spouse would like to have children but fear the repercussions of your children inheriting the mutation. You have heard that there is a doctor who can do in vitro fertilization and then test the cell clusters to determine which do not have the mutation and then implant those healthy embryos. There are currently no laws regarding the testing of embryos for genetic flaws.

If you were a public health advocate, what factors need to be considered when determining whether this procedure should be legal in Canada?

Discussion #3: Genetics and Predispositions

a) You are in charge of a life insurance company. You are tasked with determining if and when to provide insurance to people with identified genetic predispositions. For example, one of your clients has a 75% chance of developing breast cancer in her lifetime and is currently 25 and healthy. What factors need to be considered as you determine your policy on providing life insurance to such a person?

b) You are the owner of a large company. You are tasked with determining whether or not to hire a senior vice president who has a genetic mutation which may see him dead by the time he is 50 years old. Furthermore, as he ages he may be forced to take more and more time off to deal with his condition. What factors need to be considered as you determine your policy on hiring people you know to have genetic weaknesses?

Discussion #4: Genetic Mutations and Children

a) You have a diagnosed genetic mutation and your spouse knows about it. In planning for your future you begin to ask questions about having children: you currently have none. Knowing that you have a 50% chance of passing on your mutation to your children, what factors need to be considered (if any) as you determine if you want to have kids?

b) You have a diagnosed genetic mutation and your spouse knows about it. You currently have two children who are aged 6 and 8. Knowing that each child has a 50% chance of having inherited your mutation, what factors need to be considered (if any) as you determine what to tell them and when to have them tested?

Here are some of the notes that I work from

The focus of the workshop (objectives) is to do three things:

1) To introduce them to the reality of the use of genetics in healthcare and in everyday life (eg., 23-and-me as well as Ancestry.com's use of genetics to connect, seemingly disparate, family trees)
2) To challenge them to be engaged and thinking members of their society, their faith communities, and their families.
3) To challenge them to formulate a basis for ethics and then to use that basis to come to ethical conclusions, acknowledging the strengths and weaknesses of their position and being able to identify what the bases are for the foundation of the positions of others.

The core of the teaching component is a class discussion about some genetics-related topics such as: heredity vs. environment and the insertion of freedom and choice into the equation; current questions of genetic testing and the implications (positive and negative); eugenics and the quest to rid our species of unwanted genetics (the practical side of the abortion debate).

Possible topics for discussion:

- Taking out the question of the ethics of abortion as a practice, that is, assuming that abortion is a neutral tool in reproductive technology, discuss the pros and cons of invitro fertilization (IVF) and embryo selection based on adherence to normal human genome. Eg., how do we determine what normal means and what traits are acceptable to screen for?

- 23 and me is a service which does a genomic analysis on a DNA sample and returns a report of known genetic flaws and predisposition to disease. Discuss the benefits and hazards of such a test?

- Disease predisposition based on genetics is the statistical likelihood that any one person might get a particular disease based on his or her genetics. As it relates to health care and insurance, how should predispositions be viewed?

- Discuss what it means to be a responsible parent as it relates to genetically heritable syndromes. Issues to discuss include: should people who have heritable syndromes have biological children? and When is it appropriate to have children tested for heritable syndromes if a parent has one?

About the Presenter

Dennis Maione keeps bumping up against cancer. Diagnosed with colorectal tumour as a young, newly-wed student, he thought his subsequent victory would set him up for a straight run at life. A decade later, however, he found out he had a genetic anomaly. Fifteen years after his first diagnosis, the entrepreneur and father of three faced a recurrence of colon cancer, and the second round exacted a higher toll from him than the first. In November of 2017 marked his second 10-year cancer-free anniversary.

Dennis has wrestled a strong enemy with grace, wit, and humour. His first book, *What I Learned from Cancer* (2014, Prompters to Life), chronicles cancer, genetics, and medicine, but mostly hope. Insights into the soul of a cancer survivor abound throughout the narrative, reflective essays, and conversations with a doctor. You'll meet the community around Dennis, including many physicians–good and bad–and heroes in the unlikeliest of places.

Dennis wrote the one-man play *Three Things: Stories About Life* in 2016 with a 5 show run performed in the summer of that year.

His current writing project, *Finding Wholeness*, is the end to the cancer series.

Dennis Maione is an author, speaker, teacher, and actor living in Winnipeg. He has a B.Sc. in Computer Science and two Master's degrees in pastoral theology. When not writing, Dennis delivers seminars for high school students and speaks to groups about finding hope and wholeness in the midst of chronic disease and critical life circumstance. Dennis is a board member of the Manitoba Writers Guild (MWG) and is a member of The Writers' Union of Canada. These days he can also be found on Friday nights managing Station 8 Café, a purveyor of fine coffee and grilled cheese at 325 Talbot avenue.

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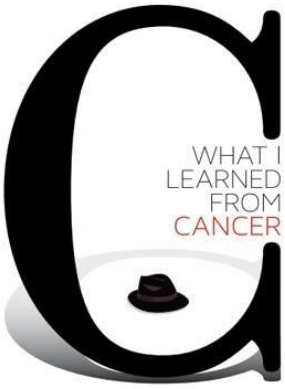

Price Matrix

One of the keys to the success of this workshop in a variety of schools, with different grades, and with different outcome expectations is flexibility. In the spirit of flexibility, the following price matrix has been drawn up. Because, in all facets of this workshop, I strive to be flexible, this matrix is only a starting point.

Standard Workshop: 1 x 1-hour sessions = **$100 + GST**

Additional workshop days added to the standard day = **$75/day**

Class set of books (20 or more) = **$15 per hardcover copy** of *What I Learned from Cancer*.

If your classroom is not in Winnipeg, an additional travel surcharge will be negotiated = **$variable**

If your school would like to arrange for this workshop—in a condensed and accelerated form—to be presented to your science teachers so that they can teach it themselves that can be arranged. Contact Dennis Maione for availability and pricing.