

Public Health Genetics Case

DAY 1

You are enjoying a lazy Sunday morning, drinking coffee, enjoying sunshine in Seattle, and checking Facebook to see what your friends have been up to over the weekend. You see the usual – music videos, birthday wishes, complaints about rude drivers and entitled pedestrians – but one status update puts butterflies in your stomach.

Your former coworker, Dawn, has been battling colorectal cancer for the last year. You know it has spread to other organs, including her liver, and she is now starting her fourth round of chemo. She seems to have a particularly aggressive form of cancer. Dawn has been amazingly positive about her experience with cancer, and you have always considered her to be one of the most kind, thoughtful people you know.

Her Facebook post is a scathing critique of our medical system. Dawn writes, “I’m only 43 years old and none of my direct relatives have had colon cancer. How messed up is it that my cancer wasn’t diagnosed early enough because we tell people to wait until they’re 50 to get screened for colon cancer?! I can’t believe I’m just some weird statistic!” She continues angrily, saying that people should rally to lower the screening age for many cancers, and that too many health policies are based on bad data and cold statistics.

You feel for Dawn, but you can’t help but feel anxious about what she’s written. After all, as the newest research associate at Northwest Pacific University, you know that decisions made about screening age and frequency consider many factors – population health statistics, study outcomes, the biology of cancers, risk-benefit analysis, and even economic impact evaluations. You know there will always be outliers, but decisions about population health can’t consider every individual anomaly. Thinking about this makes you pause. Have you become one of the hard-hearted people that Dawn was complaining about?

When you get to work on Monday, you are asked to join an unexpected team meeting. Your principal investigator has been awarded a large research grant to investigate health disparities in colorectal health outcomes. She has already been involved in some partnerships with the health department to create programs to reduce the incidence of colorectal cancer in King County. Despite this, your supervisor feels that there isn’t enough baseline data about colorectal cancer in Seattle, let alone about health disparities. She wants you to help her design a local study that would help the team understand more about the burden of colorectal cancer in King County. The results of your study could help the health department and other agencies design more targeted interventions to reduce colorectal cancer incidence and reduce health disparities. You are flattered she has asked for your help, but you also feel nervous, since this will be your first time designing a study after finishing graduate school.

Not everyone in the room seems happy about the possibility of this new project, though.

“Guys, I really think we need to look carefully at whether health disparities even exist in our city for colorectal cancer. The last time I checked, Washington State was doing pretty well, across races,” says Bill.

Anita chimes in, “And don’t you think we should take a close look at whether there are biological differences between different races? Even if there are differences in incidence and prevalence, maybe there are genetic or epigenetic factors that are at play. If that’s the case, then will it really matter if we try to promote screening or create a program that addresses supposed behavior or environmental factors?”

Devon, an African-American woman, seems to be offended by this. “Look, we already know that racial health disparities exist, and people of color often get the short end of the stick. My cousin got breast cancer when she was 25, and we don’t have any family history of breast cancer. So are you telling me it’s not worth trying to improve health care and access to health care for people of color? It doesn’t matter what the cause is.” This reminds you of Dawn, and you get that uncomfortable feeling again.

Your supervisor steps in to diffuse some of the tension. “I think this is where we can help,” she says, gesturing to you. “We can design and implement a study that will help us understand whether biological, environmental, or social determinants of health make a bigger difference here in Seattle.”

There is more conversation in the room, but you start tuning it out, feeling excited by the opportunity to learn more about the community you live in. You start wondering about your sample size and how you will recruit study participants, your favorite part of the job. You also wonder about how you are going to research biological differences, since you neither have the background nor the facilities to do this. Who might you partner with? And what type of information will yield the best information? You decide a lit review is in order, to determine what researchers already might know about the determinants of colorectal health outcomes.

Later that day, you run into Devon in the staff lounge. She confides to you that she feels embarrassed by her outburst in the meeting, but you reassure her that you knew where she was coming from. You also confess to her that you have some concerns about your study. Ever since *The Immortal Life of Henrietta Lacks* came out, you think there’s been even more buzz than usual about people – especially from the African-American community – who feel very suspicious about the scientific community. Devon says she can’t represent her entire community, but she reminds you that it can always be difficult to establish a good relationship with study participants, especially when you don’t have a shared background. You leave feeling even more motivated to do a good job on this project.

Idea for Day 2

- Decision Analysis and ICER
 - New screening intervention with risks
 - Decision tree
 - Calculate ICER
- Need to make hypothetical cost data
- Hypothetical intervention? (or hypothetical treatment?)

Learning Objects

- select study design
- describe methodology -- sample selection, size, etc.
- explore history of racism and genetics research
- analyze health disparities of a disease
- present commentary on a screening or policy recommendation
- understand the biology and epidemiology of a disorder
- appreciate the relationship between genetic epidemiology and public health practice