The Data of Disease:

How Data Collection Leads to Healthy Populations

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Families in the 18th and 19th centuries commonly had many children, simply because children in these time periods had a much greater risk of dying due to infectious disease, poor sanitation, and poor nutrition than many children alive today. Vaccines, good sanitation practices, better food availability, and access to healthcare have reduced childhood mortality, and led to what scientists call an "epidemiological transition:" fewer children dying leads to smaller families, which in turn create larger, older populations in which the main causes of death are no longer infections, but instead chronic diseases.[1]

In this century, chronic diseases are the major cause of death and disability worldwide.[2] By definition, a chronic disease is one lasting three or more months.[3] These conditions are persistent: they generally cannot be prevented by vaccines or "cured" by medication, rarely "just go away," and are the leading causes of death and disability in the United States.[4] In 2005, almost half of all American adults had at least one chronic illness, and by 2009 the U.S. was spending more than 75% of our healthcare budget on chronic conditions.[4] In 2015, 67.7% of Medicare-enrolled persons over the age of 65 years had two or more chronic conditions, and those numbers are still rising.[5]

Now the question researchers are asking is, "what can we do about it?"

Epidemiology and Biostatistics: Why Math is Important

When studying a disease, one of the first things scientists look at is the incidence – what is the rate of new or newly diagnosed cases of a disease? Incidence rate is a very good indicator for infectious disease, because it shows scientists the "first" time someone has the disease. Incidence can be further categorized into different subsets – we can look at the incidence rate based on gender, or racial origin, by age group, or by diagnosis.

When studying chronic disease, however, we need to look a little deeper. Researchers look at the prevalence – the actual number of cases, either at one specific point in time (point prevalence) or over a period of time (period prevalence) that exist in a community.

Incidence and prevalence work together, but which is more important depends on the disease. In the case of a flu epidemic, the incidence rate (the number of people catching the flu) may be very high. But because many people recover after a few weeks, the prevalence of the flu may be very low. In the case of a chronic disease, like cancer, the number of new cases in a given time period may be very low, but the total number of cases may increase, because people are living with the disease.

As we transitioned into a society in which more people died of chronic disease than they did of infectious disease, scientists had to re-think the disease process. They wanted to know what the underlying causes of chronic disease were, if they could be prevented or controlled, and what

impact these diseases have on the health of individuals and communities. To answer all these questions, they needed data.[6]

Risk vs. Protection

There are several diseases that meet the definition of chronic: cardiovascular disease (heart disease and stroke), cancer, chronic respiratory diseases (chronic obstructive pulmonary disease (COPD) and asthma), diabetes, and a slew of other conditions (mental disorders, vision and hearing impairments, oral diseases, bone and joint disorders, genetic disorders, etc.).[2]

In the 1960s, researchers began to use large-scale studies like the Framingham Heart Study, the Seven Countries Study, and the British Doctors Study to determine why people were getting sick. By looking at such large groups of people, researchers could see trends in the data: they discovered that the presence of certain things – "risk factors" – put people at a greater risk of contracting a disease, and other things – "protective factors" – tended to keep diseases from happening.[6] They also found that some risk factors (primarily cigarette smoking, poor diet, physical inactivity, and high blood pressure) could contribute to multiple chronic diseases.[6] No study has found the "cause" of chronic diseases, but using different studies, different study designs, and different populations of people, scientists now know that there are many factors that can increase (or decrease) an individual's risk of disease.

The WHO lists several risk factors of chronic disease, some modifiable and some not. Modifiable risk factors include an unhealthy diet, physical inactivity, consumption of alcohol, and tobacco use. Non-modifiable risk factors are things like age and genetics. As research has continued, so-called "intermediate risk factors" like high blood pressure, high blood glucose, and/or being overweight or obese have been found to contribute to the development of chronic disease.[2] Researchers also believe that the Social Determinants of Health are fundamental causes of chronic disease. The conditions in which people grow, live, work, and play; the factors affecting their daily lives; their ability to access fresh food, health care, and exercise; their mental health and ability to handle stress – all of these things have been found to contribute to chronic disease.[7] By gathering data, researchers can focus prevention efforts to target risk factors specific to communities.[6]

By contrast, certain factors can prevent or protect against the development of chronic disease. Regular consumption of fruit and vegetables, access to healthcare services, and the ability to maintain an exercise regimen have all been shown to decrease the risk of chronic disease within a community.[8] Preventive screening for different types of cancer, heart disease, and other chronic diseases have been shown to avoid or delay the onset of disease, keep diseases from getting worse, reduce healthcare costs, and allow people to lead productive lives.[9] Making lifestyles healthier by providing access to basic utilities, making streets and neighborhoods safer, decreasing socioeconomic class differences, and providing social support can lead to healthier diet choices, tobacco and alcohol cessation, and healthier habits.[7]

All of this data - incidence rate, prevalence rate, risk factors and protective factors – are based on populations, not a single individual. While individuals living in the same community may have some of the same risk factors (clean air, abundant outdoor spaces, access to fresh food), other factors are likely different (smoking tobacco, genetic factors, ability to access healthcare). It is the interaction of these risk and protective factors that may lead an individual to be diagnosed

with a chronic disease. Unfortunately, there are no absolutes: just because an individual has all of the known risk factors for asthma, does not mean that she will suffer from it.

Where do we go from here?

Thirty percent of adults living in Kent County reported that they have no leisure-time physical activity. In Sussex and New Castle Counties, that number is 27% and 25%, respectively.[10] In Kent County, there is one primary care physician for 2,200 people; in Sussex (1 to 1,530) and New Castle (1 to 1,230) those numbers are better.[10] In 2015, non-Hispanic white adults were more likely than non-Hispanic black adults to die of coronary heart disease in Delaware.[5] Non-Hispanic black Delawareans are almost twice as likely to have diabetes than non-Hispanic whites, and are more likely to be obese or overweight.[5] Using data like this, programs and institutions can direct their resources to people in high-priority areas like the City of Wilmington or Sussex County, update their disease screening protocols, or add prevention programs in high-risk communities.

At this point in time, researchers cannot pinpoint one or multiple factors that will accurately predict if a person will or will not be diagnosed with a chronic disease, although there are many interesting opportunities for personalized medicine in the very near future. Researchers are learning how to tailor interventions to people based on their personal risk of disease or expected response to treatments. More and more, scientists are noticing that some risk factors occurring together increase a person's risk of many chronic diseases. It is only by continuously gathering data, and looking at that information on a population scale, that we will continue to fight the chronic diseases that are present in our communities.

There are many institutions, non-profits, volunteer organizations, and individuals in Delaware committed to reducing the burden of chronic disease in the First State. Indeed, this is the basis for the newly formed Delaware Chronic Disease Collaborative (www.dechronicdiseasecolaborative.org). Over 74% of Medicare-enrolled Delawareans over the age of 65 years have two or more chronic conditions, and 10% of all Delawareans over the age of 18 have diabetes. Over 30% of adults are considered obese, and almost 50% of persons in Delaware have had a stroke.[5] By working together, organizations throughout the state can decrease the burden chronic disease places on our communities, families, and individuals.

Data are used in institutional decision-making every day, and the healthcare industry is no different. Planners all over the state use the data gathered by state, federal, and local institutions to direct their funding, plan their projects, and evaluate the effectiveness of those programs on an ongoing basis. In this way, individuals - in Delaware and across the nation – can get the most up-to-date health information as soon as possible, and live their healthiest lives.

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