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EDITORIAL

Commentary to "My Identical Twin Sequenced Our Genome": Cautionary Genomics

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The commentary by Schilit and Schilit Nitenson in the current issue (Schilit and Schilit Nitenson 2016) offers important insights into the prospect of whole genome sequencing. The authors, monozygotic twins, describe their experience after one of them chose to pursue the test over the misgivings of the other. Although genetics professionals routinely discuss the family implications of genetic testing, the particular ethical and practical questions raised by testing a monozygotic twin have not been fully explored. In this case, the test was ordered by a primary care provider who failed to address the issue during pre-test counseling.

One of the questions implicit in the commentary is whether a monozygotic twin should pursue whole genome sequencing in the absence of her twin's consent. As Schilit and Schilit Nitenson note, the legal perspective on this question is clear-cut: a competent adult, even a monozygotic twin, can make an autonomous decision about medical testing. But from an ethical perspective, should she do so? What the authors show us is that family members owe an ethical duty to each other when considering their shared genetic risk. It is a nuanced duty that need not compromise individual choice, but does require honest and caring communication.

Would Schilit's and Schilit Nitenson's story have been different in any essential respect if they had talked first to a genetic counselor? I doubt it. A genetics professional would surely have provided better counseling than Schilit received. She would have discussed the implications of testing for the patient's twin, offered to meet with the twin, encouraged discussion before the test, and offered guidance on how results might be shared after testing was done. But the open and thoughtful discussion of motivations, doubts and, ultimately, results would likely have happened exactly as it did. Schilit and Schilit Nitenson have modeled the kind of process we should encourage in this unusual situation. Their story is instructive for genetics professionals who are likely to encounter other twin pairs less aware of the implications of genome sequencing, less able to communicate effectively, or less willing to offer each other both freedom and support.

However, there is another important point embedded in this story that we would do well to contemplate. Schilit describes her excitement at the opportunity to have a whole genome test, her sister's trepidation, and the disappointment with which she received her generally uninformative results. All of these reactions stem from the inflated predictive value we have assigned to the genome. Schilit anticipated that the genome might provide invaluable health information, and the counseling prior to testing emphasized the potential social or psychological consequences of the risk information she might receive. This kind of messaging raises unrealistic expectations about genomic information, which is not likely to be particularly informative or interesting for most people – as was the case for Schilit and Schilit Nitenson. They undoubtedly benefitted from learning that they did not have a known inherited cancer syndrome, given their family history. Beyond that, it would have been appropriate for them to have low expectations. In part, as they note, the genome is still difficult to interpret; our ability to distinguish truly pathogenic mutations in individuals without a priori risk remains poor (Van Driest et al. 2016).

For most of us, however, the question is not whether we harbor a rare genetic disease. Rather, it is whether genomic information can help us to address the common complex

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disorders that are the main cause of death and disability in our society – diseases like diabetes, heart disease, stroke and most cancers. We have learned over the past decade that genetic risk for these conditions is conveyed by multiple gene variants in dozens or hundreds of genes, each with very small effects. Overall, the genetic contribution is modest compared to the substantial impact of social and environmental factors on these disorders (Schroeder 2007; Banks et al. 2006); in the words of CDC Director Thomas Frieden, "your longevity and health are more determined by your zip code than they are by your genetic code" (Weintruab 2014). Individuals with a scientific bent may enjoy rummaging in their genome, but they should not expect it to inform them about their future health.

For well-educated people who live in safe environments, this is good news. These characteristics alone confer a health advantage, which can be further augmented by prudent lifestyle choices. Such choices are likely to prove far more important to a person's future well-being than information obtainable from a genome sequence.

Compliance with Ethical Standards

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Conflict of Interest Wylie Burke declares that she has no conflict of interest.

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