Testing Knowledge

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Testing Knowledge: Toward an Ecology of Diagnosis, Preceded by the Dingdingdong Manifesto.

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The call from my sister Nancy Wexler still resounds in my mind. “We found a marker!” she shouted over the phone. It was the summer of 1983 and Nancy had helped lead the team of geneticists and neurologists who had just mapped the gene for Huntington’s disease (HD), an incurable hereditary motor, cognitive, and psychiatric disorder. Huntington’s had claimed the lives of our mother, uncles, grandfather, and cousins over multiple generations. The discovery of the genetic marker – a variable stretch of DNA on chromosome four, located close to the Huntington’s gene – was a giant step toward finding this gene and, we believed, developing a cure, or at least ways to prevent or mitigate the disease’s cruelest effects.

The marker also made possible a predictive or presymptomatic test. Geneticists and neurologists had long dreamed of such a test and so too had many families like mine. Huntington’s is an autosomal dominant disorder – meaning that each offspring of a parent who develops symptoms has a 50% risk of inheriting the disease. Typically these symptoms emerge in a person’s thirties or forties, or even later, after children are born. A predictive test using the genetic marker – and ultimately the gene, discovered in 1993 – could indicate who among the offspring was free of the disease and who had inherited the abnormal gene and could pass it on to their children.
Many of us believed such a test, chosen freely by the individual concerned, could alleviate anxiety and dread in the lucky ones and at least facilitate future planning for the others. After all, a positive predictive test result—sometimes called a positive genetic diagnosis—did not mean you were ill in the present; it was strictly a prophesy for the future.

But what kind of prophesy? Predictive genetic testing turned out to be more complex, more challenging, and more ambiguous in its impact than we imagined, as Katrin Solhdjju shows in her compelling and powerful book *Testing Knowledge: Toward an Ecology of Diagnosis*. As disclosed to Alice Rivières, a brilliant young French psychologist and writer, the predictive genetic test result for HD foreclosed any future other than deterioration and decline. “The doctors I met with were both terrified and fascinated by what they were having me do,” writes Rivières. In possession of a powerful new technology, “a destiny-making machine,” they suffered from a devastating failure of imagination that reduced “the multiplicities of tomorrow into a narrow, monolithic, flat, diagnosed sick future that stops the mind from the business not of grieving but of creativity.”

*Testing Knowledge* builds on Alice Rivières’s “ruinous” experience, which Solhdjju interprets as both a cautionary tale and a provocation. She does not condemn a particular clinician or the (French) medical establishment for conveying a genetic test result in a brutal manner, as if it were a foreordained sentence to suffering. Instead she takes Alice Rivières’s encounter as a starting point for improvisation. She asks how we can “cultivate an ecology of diagnosis that could place all actors involved in situations where they become capable of acting to the fullest extent possible.” How can we develop narratives of Huntington’s that fully acknowledge the variability of this illness, that situate those living with HD as actors rather than as passive victims, and that allow doctors and
scientists to say “I don’t know” in the face of uncertainty and ambiguity. She asks for “celebration without denunciation,” that is, for celebrating hard-won biomedical advances – as of 2021, medications for chorea and clinical trials for gene-lowering therapies – while valuing alternative non-medical ways of knowing and responding to disease.

Even as they recognize the severity of Huntington’s, Solhðdjú and Rivières reject the tragedy narrative and eugenic assumptions that run through much of the discourse on this illness. They ask instead, how can we live better with such a disease? How can we use Huntington’s as “an opportunity to push thinking further?” As predictive and prenatal genetic testing becomes possible for a widening range of conditions, Katrin Solhðdjú shows us that, more than ever, we need the voices and knowledge of the users. We need our collective imaginations, fantasies, and “speculative narrations,” from outside medicine and science as well as from within, to invent a future in which all of us, with Huntington’s as well as without, may flourish.

– Alice Wexler, Santa Monica, California, January 2021