

Monica Konrad.

Narrating the New Predictive Genetics: Ethics, Ethnography and Science

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Huntington's Disease (HD) is a monogenic (single-gene) inherited disorder of the central nervous system. Typically appearing in adults in mid-life and lasting for ten to twenty years or more, its symptoms are quite devastating, including involuntary movements, dementia, personality changes, gradual loss of speech, and general deterioration of the reflexes (including swallowing, which often leads to choking as a cause of death). There is no known cure for the disease, however genetic testing has been available to families since 1986.

Using detailed testimony from interviews with twenty-four British HD families (though she includes data from only six) and other experts, *Narrating the New Predictive Genetics* explores the implications and ethics of this genetic testing and especially what it means to become classified as "pre-symptomatic." The book seeks to demonstrate that this designation is morally complex and relational – factors that current practices, policies, and debates over the "right to know" do not appear to recognise. *Narrating the New Predictive Genetics* also underscores the critical role that ethnography could play in bioethics debates over genetic testing. Here the author, a social anthropologist, contends that her discipline has been too slow to theorise the relation between health, ethics and human rights, thereby enabling these debates and subsequent policies to remain out of touch with the actual experiences and needs of HD families.

To this end Konrad uses rich ethnographic data to demonstrate especially what a significant impact the knowledge "gained" from genetic testing for HD can have on peoples' lives and everyday social relations. Vivid interview excerpts are used to show that prognosticating a person's health through predictive genetics is never simply a matter of objectively interpreting certain genetic markers and drawing correlations between alleles. Rather, becoming "pre-symptomatic" is an extended and ethically charged process, one that can span the period of time during which the at-risk individual must: deliberate over whether or not to have the test done, wait for the test result if s/he has chosen to go ahead with it, and then deal with the fallout (both moral and familial) afterward. Indeed, new genetic testing raises a host of ethical dilemmas into which ethnography could provide insight; these include questions of when and if to test, disclosure (who to tell, when to tell, when to respect someone's wishes not to know), reproductive choice (to proceed or not with a given pregnancy), and how to live one's life. It is this lived experience of be(com)ing "pre-symptomatic" that Konrad illustrates with great finesse. In particular, she shows how having this genetic knowledge in one's possession does not mean that the testee will know how to act on it. There is no ethics handbook for people to follow and to guide them through the series of decisions that emanate from receiving a positive test result, or even the decisions that must be made by the untested person seen to be at risk.

From this study we also learn that testees were not simply passive recipients of the information regarding their genetic status given to them by health professionals, and that there are no clear beginnings and endings to their stories and experiences of be(com)ing "pre-symptomatic." This plays out especially in terms of how they deal with the information in the context of their families.

That is, an individual's test result is never relevant only to her or him, since the fact of being a single-gene autosomal dominant disease means that a test result can implicate one's entire family. In particular, test results can strain family relations between, for example, siblings who discover that they do not share the same genetic fate, or between a parent and child(ren) who may – or may not – want to know their genetic future. This points to a further contribution of the book, namely its exposure of the myth of pre-emptive individualism that informs current genetics practises. For example, genetic counselling is meant to be non-directive, yet testees are encouraged to share their results. Similarly, individuals thought to be at-risk (e.g., the children of a parent with HD) are increasingly being co-opted into becoming health-seeking citizens who do the “responsible” thing and get themselves tested.

Narrating the New Predictive Genetics makes an original and important contribution to current scholarship on geneticisation by expanding the normative definition of bioethics beyond rules and principles to illuminate the “relational ethics” involved in HD decision-making. Refreshingly self-reflexive (see, for example, Konrad's discussion of one informant, Lucy, whose physical difficulties she inadvertently overlooked during the course of one interview), Konrad combines anthropological insight into kinship and morality with bioethics and shows how the social and natural sciences might well converge to help produce better policy rooted in how individuals and families *really* respond to genetic information, rather than *assumptions* about what their reactions will or ought to be.

However, Konrad's homogeneous sample (typically white, heterosexual, middle class and Protestant Brits) and her exclusive focus on Huntington's did leave this reader wondering if her argument and analysis would extend as seamlessly as she asserts (but does not demonstrate) to other, equally severe genetic disease contexts (e.g., autosomal *recessive* disorders such as Tay-Sachs), or to different religious or ethnic groups whose moral-decision making takes place in terms of certain culturally specific considerations and norms especially with regard to reproduction.

Despite this gap in the argument, I strongly recommend *Narrating the New Predictive Genetics* to scholars interested in issues pertaining to genetic testing, as well as the political (and ethical) potential of ethnography. It is pitched rather high and uses a fair bit of jargon, however the book could work well in graduate courses on the sociology of knowledge, science and technology studies, medical anthropology and sociology, and possibly courses on ethnography. I do not think it is accessible enough for undergraduate courses.

Shelley Z. Reuter
Department of Sociology and Anthropology
Concordia University
sreuter@alcor.concordia.ca

Shelley Z. Reuter is an Assistant Professor specialising in the sociology of health and medicine. Her current research deals with the history and politics of Tay-Sachs disease.

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