

Book Reviews/Comptes rendus

MONICA KONRAD, *Narrating the New Predictive Genetics: Ethics, Ethnography and Science*. Cambridge University Press, 2005, xii + 203 p.

Monica Konrad writes about an important subject that concerns the practice of early medical testing made possible by new predictive genetics technologies. *Narrating the New Predictive Genetics* studies the ethical implications of testing those who have potentially inherited Huntington's disease (HD) while they are still pre-symptomatic. This issue is especially relevant considering the rapid rise of genetics testing and DNA research that is exploding across the scientific, legal, and medical landscape. Most centrally, the book represents a case study in the ethics of disclosure and non-disclosure that is made possible by the emergence of predictive technologies as they apply to families coping with this hereditary disease. It is also an evaluative book that challenges the official (individualist based) ethics policies of the medical institution with evidence from the much more social, contextual, and relational ethics practiced by families as interdependent, emotionally attached groups.

The data she presents is very rich, with vivid and often painful descriptions of the family dynamics of ethical decision making as it relates to the issue of pre-symptomatic testing for themselves and their families. She illustrates beyond any doubt that these choices are never made as individual, ego-centric decisions, but are enacted through constant cooperation and conflict with spouses, children, parents, and siblings. Her data include twenty-four families from across England as well as Scotland, Wales and Ireland. Families, rather than individuals, were chosen as the unit of analysis in order to understand the social and contextual dynamics at work. This approach shows the value of the researcher moving beyond an individualist approach to interviewing, and illustrates the conceptual gains of interviewing groups of connected individuals for a better understanding of the relational quality of so-called individual decisions.

Despite these good intentions, she actually presents data from only six families. This raises questions about the quality and consistency of her data, and her seemingly selective sampling of cases to present. This also led me to wonder about the strategy of presenting individual vignettes of one or two families in a chapter. It may have been better to organize things more conceptually, bringing in textual examples from as many families as possible with each theoretical point, to show that the findings presented are not overly case-specific. In short, if Konrad has done the legwork of interviewing so many families across the UK, why not make full use of her

data? I also would have liked to see more data on the negative side of people living with Huntington's disease who refuse genetic testing. What are the struggles of living pre-symptomatically, and not knowing whether you will develop Huntington's disease? Surely this long term uncertainty is an experience that is both frustrating and fearful. Can one really understand the problem introduced by predictive technologies without a comparison with the experiences of those who have to live without knowing? This sort of data may have softened what seems to be a significant undertone of contempt for the new predictive technologies seen throughout the book. While I appreciate the need to tread carefully as these technologies expand, and rethink these ethical issues of disclosure appropriately in contextual and relational terms, one can only assess the problems introduced by predictive technology against what it is like to live without it.

Conceptually, I think, the work is left wanting. While she links her research on predictive genetics to anthropological studies on diviners and prophets from tribal cultures, these comparisons are fleeting, and do little to inform the contemporary case. The theory section is presented at the beginning of the book, with some promising possibilities, but it is never really used in a thorough-going way to inform her field research directly. The very best field studies seamlessly interweave contemporary theory with rich excerpts from the data in ways that shed light usefully on the case at hand. In this sense, I am afraid that Konrad's study falls short. Still, the book represents a rich exploration of the ethical dilemmas of disclosure associated with new genetic testing technologies, and the families who are struggling to negotiate this uncertain terrain. Further, it shows the weaknesses and limitations of individual-centered ethical mandates of disclosure, by illustrating that these issues are highly relational and contextual in practice. Those interested in medical ethics stand to learn a great deal from the findings presented in this book.

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