



Dorothy C. Wertz 1938–2003

Bartha M Knoppers

Dorothy C. Wertz died suddenly on April 29th while attending the annual meeting of the Ethics Committee of the Human Genome Organization. She was 65 years old. Dorothy's achievements in international and crosscultural research on ethical and social issues in genetics are extraordinary. From when we first met in 1989, Dorothy was a true friend. I was in awe of her. I still am.

The path Dorothy took to become a bioethicist was not an ordinary one. A graduate of Radcliffe College in social relations, she studied social anthropology at the London School of Economics and completed a master's degree in the sociology of religion at Radcliffe. She then received a Ph.D. from Harvard in religion. She taught religion and social sciences at eight New England colleges. During this time, she acquired expertise in survey and interview methods and in statistics. Her research in public health and human genetics began at Boston University. With James Sorenson, Dorothy did the first empirical evaluation of genetic counseling in 1979–1980. Dorothy was an expert on why counseling succeeds or fails.

In the mid 1980s, she and John Fletcher surveyed medical geneticists in 18 nations on approaches to ethical problems in counseling, screening and prenatal diagnosis. The book *Ethics and Human Genetics: A Cross-Cultural Perspective* (1989) is the culmination of that research. In the mid 1990s, they conducted a second study, expanding their research to 37 countries. Their second book, *Genetics and Ethics in Global Perspective*, will be published by Kluwer International. Each nation that participated in their research is better off because of it; through participation, some professional genetics societies debated ethical issues openly for the first time.

Dorothy made a substantial contribution to knowledge about the practices and cultural attitudes that affect the genetic decision-making process. She coedited or wrote seven books, 75 articles in peer-reviewed journals, 43 book chapters and numerous reviews of books in professional journals. From 1991 until shortly before her death, she was senior scientist in social science, ethics and law at the Shriver Center for Mental Retardation in Waltham, Massachusetts.

She was a researcher with impeccable integrity. Her early 1990s research on the attitudes of women to prenatal diagnosis debunked the prevailing theory that women were being duped or were victims of the technology. Her work with Canada's Royal Commission on New Reproductive Technologies bears witness to this seminal research. In the Social Issues Committee of the American Society of Human Genetics, she was unflinching in arguing for greater autonomy for adolescents in decision-making in genetic research and testing.

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Dorothy traveled to genetic centers all over the world, lecturing on her research, encouraging public education and helping geneticists in developing nations make a plan for professional and public debate of ethical issues. Dorothy was a voice for justice in health care, education and women's rights across the globe.

Known for her clarity in writing and speaking, she could explain complex genetic and scientific issues to lay audiences and was very active with genetic disease support groups. She was among the first social scientists to include individuals with genetic diseases, professional geneticists and other physicians in the same studies.

Perhaps the venue where we worked together most closely was the Ethics Committee of the Human Genome Organization. Dorothy volunteered to work on every Statement after becoming a member in 1998. In particular, the Statements on DNA Sampling (1998), Benefit Sharing (2000), Gene Therapy (2001) and Human Genomic Databases (2003) profited from her research, her insistence on coherence and her endless verbal 'pruning'. No shortcuts for Dorothy!

Those who attended these meetings and others with Dorothy know that she was fearless at the microphone, usually the first to ask questions, and that she always had data. Gathering information from so many countries, traveling to Nepal, Tibet and Mont St. Michel (to the top with me), she visited places few of us would tread. She concocted research projects that were innovative and adventurous, like her.

Dorothy's paper on "Genetic Discrimination in an International Context," published in *Populations and Genetics: Legal and Socio-Ethical Perspectives*, illustrates her commitment both to basing analyses of social issues on facts and to providing the views of different cultures. Dorothy was a true internationalist with much vision and no fear. *Populations and Genetics: Legal and Socio-Ethical Perspectives*, recently released by Martinus Nijhoff Publishers (Leiden), is dedicated to Dorothy.

Open to changing her mind (unless the facts proved otherwise), without pretension, an incorrigible editor, and a lover of eccentric jewelry and hats, of dogs, of good food and of the company of her friends around the world, Dorothy Wertz was larger than life. Her international family will truly miss her. ■