

We would like to respond to three issues that we consider key to the stance taken by Angus Clarke in his reply to our report of a single study.

(1) Clarke questions the usefulness of data from situations that have some aspects in common with, but are different from, the situation of interest. In this case, the situation of interest is whether parents should be allowed to have their children tested for genes for late onset disorders for which there are no medical interventions. Because of the difficulties of gathering data directly to inform this question, we studied the responses of parents to having their young children tested for a condition for which there is a medical intervention. Some of their responses related to the practical implications. The majority, however, related to the psychological implications of having knowledge for its own sake, with relief brought about by greater certainty. We consider further larger scale and controlled studies of this, and other conditions, will help inform the more ethically problematical situations of genetic testing for conditions for which there are no medical interventions.

(2) Clarke states: "A focus on evidence in this area, to the exclusion of ethical reflection, may be understandable when it comes from those who are professionally engaged in gathering evidence, but it should not blind physicians and other health professionals to their obligations towards their patients and clients." Evidence and ethics should not be counterposed, but used to inform and enrich each other. Similarly, those who gather evidence should not be counterposed against those who have clinical obligations to patients. Without evidence, no amount of obligation will guarantee high quality care. And those engaged in health services research have the care of patients as the prime objective for their work.

(3) "It will be essential that the evangelists of evidence remember that researchers have a duty of care towards their subjects, just as clinicians do towards their patients", writes Clarke. One of the reflections of the developed sense of duty of care by researchers towards research participants is the comprehensive and stringent system of Research Ethics Committees in which researchers, clinicians, and others are involved. All health workers have obligations both to the welfare of patients and to assessing continually the evidence on which their care decisions are based.

The greater the ethical, social, and psychological dilemmas associated with new developments in health care, the greater the need for relevant evidence to inform the decisions about whether, and how, to offer new services. Without this, decisions will, de facto, be made by those with purchasing, political, commercial, or medical power, decisions that will not necessarily be in patients' best interests.