

Introduction: toward a context-based ethics for social research in health

Catherine Kohler Riessman & Cheryl
Mattingly

Boston College, USA and University of Southern California, USA

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The idea for this Special Issue was born over dinner in a Greek restaurant. It was 2001 and each of us had just presented our work at a conference on narrative-based medicine in Cambridge, UK, sponsored by the BMJ. Although different issues were raised from the audience about our respective papers and others at the conference, many seemed to turn on particular questions: Were informed consent procedures followed properly? Were they sufficient to protect the confidentiality of vulnerable research participants who told lengthy narratives about their lives? Who 'owns' the stories collected during fieldwork? It is no accident that such questions should arise at a conference attended by health professionals. Institutional review boards (committees go by different names in different countries) began in the wake of massive abuses of power involving complicit physicians and nurses (Tuskegee, Nuremberg). But we sensed a narrow, individualistic and rights-oriented thrust to the comments. Like organs stolen from corpses in medical experiments, there was even a suggestion that informants' stories had been appropriated by researchers – used for academic ends, rather than to benefit patients. The model of research ethics was medico-centric, appropriate for clinical trials perhaps, but bearing little relationship to ethnographic and narrative forms of social research.

As seasoned researchers in sociology and anthropology, we had watched a medical model of ethics increase in influence on US university and hospital committees, composed largely of clinical researchers and others working in the experimental paradigm. We had witnessed the routinization of good intentions: standardized and scripted legalistic informed consent

forms designed to handle every contingency; iron-clad guarantees for research participants of confidentiality and anonymity; assumptions of privacy. At the same time, we could each point to exciting research in the social sciences that explicitly challenged inequalities (research participants reviewing and sometimes co-authoring publications, collaborative presentations at conferences, visual narrative research where anonymity may be impossible). Feminist investigators argue that research involves ongoing negotiation; taken-for-granted hierarchies of power and control over 'the data' must be questioned.

By the end of dinner, we had decided the entire domain of ethics, informed consent and narrative warranted larger exploration. Senior researchers, most of whom had worked in health, were invited to contribute articles. The articles are reflective, not traditional research reports – the form caused difficulty for some reviewers (but that's another story). All five speak to the dangers of narrow, medico-centric orientations for social research in health. Taken together, the articles open up the problematics of ethics, informed consent and narrative. While they do not present solutions, there are some directions suggested. It is not accidental that narrative figures so centrally in these articles. There are several reasons for this – we sketch a few here.

One, this kind of research concerns important events in people's lives. It is, in a word, personal. What does it mean both ethically and epistemologically to study other humans in the midst of living their lives, and to ask them to speak about matters that are close to the heart? Speaking of this in anthropology, Ruth Behar notes that such research involves 'a mode of knowing that depends upon the particular relationship formed by a particular anthropologist with a particular set of people in a particular time and place' (1996: 5). She suggests that this mode of investigating and knowing requires a 'new genre' for anthropological writing – one that features personal stories. As many scholars have noted, narratives are perhaps our primary vehicle for understanding and communicating the personal and particular.

Two, narratives have an especially critical role in studies of illness and disability. One can now speak of the 'illness narrative' literature – a multi-disciplinary and ever-growing corpus that spans the social sciences, humanities, clinical professions and popular culture. (And, in fact, many of the authors in this collection have contributed to the development of this tradition. See, for example, Loewe (2003) for a review.) The 'call of stories', to borrow an eloquent phrase from Robert Coles, has been a call for exploring life from the inside; a phenomenological concern to understand life (and disease) as lived by particular humans in their particular circumstances. Scholars of clinical practices (a number of them clinicians themselves) have examined narrative as one avenue for 'reconcil[ing] the subjectivity and uniqueness of human experience with the physical reality of the body and a larger impersonal picture' (Hurwitz et al., 2004: 3).

Three, narrative plays an increasingly significant role in contemporary critiques of traditional ethics and the rethinking of ethics generally. This third reason is perhaps the most significant and least obvious. For while it may not be difficult to understand the moral implications of taking the 'subjectivity' of the patient into consideration and the role that illness stories might play in doing so, it is less obvious why narrative should be important to a discussion of *research ethics* and informed consent. A number of scholars have proposed an ethical framework that pays special attention to the particularity and context-specific nature of practical action. Newton, in a book tellingly titled *Narrative ethics*, argues for a narrative-based ethics that attends to the 'uniqueness of the moral situation' as contrasted to the traditional attempt to develop a context-free ethical framework to guide action. He notes: 'Ethical theorists have traditionally defined freely determined action according to a law of rationality from which they can derive criteria for moral behavior at once universalizable and intrinsically intelligible' (1995: 12). Contemporary rethinking has old roots; it is sometimes called 'neo-Aristotelian ethics'. As Ricoeur points out, Aristotle argued that practical action involves 'develop[ing] a sort of understanding that can be termed narrative understanding' and that for Aristotle, narrative understanding undergirds practical wisdom and moral judgment (1991: 23; see also Mattingly, this issue for further discussion).

The articles in this collection are suggestive not only of dilemmas posed by traditional ethics, but of the need for narrative in considering what a more adequate approach to research ethics should consider. We invite readers to take the next steps for change.

References

- Behar, R. (1996). *The vulnerable observer*. Boston, MA: Beacon Press.
- Hurwitz, B., Greenhalgh, T. and Skultans, V., Eds. (2004). *Narrative research in health and illness*. Oxford: Blackwell.
- Loewe, R. (2003). Illness narratives. In C. Ember and M. Ember (Eds.), *The encyclopedia of medical anthropology: Health and illness in the world's cultures*, pp. 42–9. Hartford, CT: Human Relations Area Files.
- Newton, A. (1995). *Narrative ethics*. Cambridge, MA: Harvard University Press.
- Ricoeur, P. (1991). Life in quest of narrative. In D. Wood (Ed.), *On Paul Ricoeur: Narrative and interpretation*, pp. 20–33. London: Routledge.