

## Introduction: Ethics, health care and anthropology

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About twenty years ago, medical historian George Weisz published an edited volume under the title ‘Social Science Perspectives on Medical Ethics’ (Weisz 1990). Even though the title did not really suggest a close collaboration between the two disciplines, but rather a unilateral view from one side on the other, the book contained a number of interesting contributions. Canadian philosopher Barry Hoffmaster, for instance, argued that sociological or anthropological research into ethical issues in biomedicine could only become interesting when a principle-based approach to ethics was replaced with what he calls a contextualist approach. As long as bioethics slumbers in the armchair of unfaltering principles, empirical studies on how professionals and other people deal with ethical issues are irrelevant. But ‘[as] soon as a universal regulative method for moral decision making is abandoned, the question of how individuals in fact “muddle through” moral problems becomes interesting’ (Hoffmaster 1990). Hoffmaster further argues that positivist social science approaches are unsuitable: for social science to become relevant to ethics, it should be interpretive and interested in particulars instead of trying to reach universal results.

Ethicist Bruce Jennings, in the same volume, uses examples of ethnographic research at neonatal intensive care units to argue that ethicists need to learn from ethnographers about the everyday, nitty-gritty details and the way these impact on the way people conceptualize the moral quandaries occurring in these units (Jennings 1990). More specifically, ethnography shows ethicists that nothing is self-evident, not even the definition of what an ethical problem is.

That was twenty years ago. Why publish a special issue of *Medische Antropologie* on a similar topic, even if we avoid ‘perspectives’ talk? One reason is that, if you look at the main journals in the field of what is now called bioethics, thorough empirical studies are still a minority of what gets published. Moreover, part of the empirical work would conform to what Hoffmaster called positivist social science. The final, and most important reason is that ethicists and anthropologists alike, still struggle with the question how to really integrate the empirical and the normative. As Willems and Pols argued in a previous issue of this journal, ethics is still, to some extent, labouring under the ‘is-ought’ distinction, according to which an obligation (‘ought’) can never be deduced from the facts (‘is’) (Willems & Pols 2010). Although this distinction has been shown to be both analytically and empirically untenable, the

integration of the two is still 'under construction', and will probably remain so for a while.

Several ways to integrate social science and bioethics have been experimented with in the last two decades. Sometimes, empirical studies are used to provide the information ethicists need to build an ethical argument, sometimes, empirical studies using social science approaches are undertaken with the aim of uncovering new ethical issues coming up as medical technology develops, sometimes the main aim of empirical work is to articulate the daily work in health care institutions, thus showing the way professionals perform goodness, even if they do not always deliberate on it.

That brings us to another reason for a renewed emphasis on anthropological studies linked to bioethics: as a consequence of its being regarded as a form of applied ethics, there has been a serious disregard of the extent to which ethical concepts are developed in practices. Ethics, when regarded as an application of ethics to practices, is blind to normative innovations that occur inside these same practices. That is one of the things that empirical studies can show us. Instead of expecting progress in ethics exclusively from the theoretical work of ethicists, we had better put our stakes on innovative practices, because innovation in practices, more often than not, implies innovation in ethics.

A few years ago, one of the Dutch professors of medical ethics gave his inaugural lecture under the title 'Is medical ethics becoming shallow?' (Van Leeuwen 2007). pointing to a loss of philosophical profundity in the fixation on applicability. One of the examples he uses is about the moral status of embryos. The significance of what an embryo is, he argues, cannot be decided through an ever so brilliant ontological analysis, but should be seen as essentially linked to, or emerging from, what we do with embryos: embryos have a relational ontology. The conclusion (which Van Leeuwen, by the way, fails to draw) is simple: in order to avoid shallowness, bioethics needs to study practices in order to see the development of new, relational, objects and the normative questions they raise.

Most of the papers in this issue of *Medische Antropologie*, however, take one step further: they not only study the way practices generate new objects for ethical scrutiny, but they also show how the very content of ethics, the basic concepts and ways of reasoning are challenged when one takes a close look at practices. Studies of health care practices like the ones we present here thus do not just investigate the context of ethics, or its application, they get to the very heart of health care ethics.

The contributions to this special issue all come from an international symposium entitled 'Ethics, Health Care and Anthropology' held at Amsterdam University on December 10, 2010. To attract participants, the above mentioned article by Willems and Pols functioned as a 'teaser', introducing the subject and setting out possible lines of argument.

All papers deal with the various ways in which anthropological research can be made ethically fruitful, and/or with the ways ethical concepts and norms work out in actual practice. The papers may be subsumed under three categories:

- Conflicting values (Holten & Richters, Kristvik, Engel, Stoopendaal)
- Care and care organization (Oldenhof & Putters, Pronk, Kaufman,)
- Research (Van der Geest, Zaman & Nahar, Zwanikken & Oosterhoff).

Lianne Holten and Annemiek Richters describe the difficulties that surrounded a biomedicine-based maternal health project in a rural area in Mali. Even though the project was initiated at the request of the village, it increasingly proved to be, as the authors call it, a ‘zone of awkward engagement’ (friction) between universal standards of western biomedical midwifery and local health and gender discourses. Participant observation, convincingly shows that some of the ethical features of the project, such as the importance of informed consent, could do more harm than good if they are imported without a study of local practices and ethics.

Informed consent is the central topic of Ellen Kristvik’s paper. She shows that, even though informed consent is a seemingly clear and untouchable principle within health care, practice is a lot more ambiguous; even though Kristvik does not use the term, here too one could speak of a ‘zone of awkward engagement’, not, this time, between biomedicine and local practices, but between ethics and care practice. She studied cancer treatment in a Norwegian hospital and the extent to which informed consent played a role and how it was ‘done’. Her two cases, Alize and Bjarn, show very different ways in which patients are involved in medical decisions. These differences cannot be said to relate to their disease or the toxicity of the treatments proposed, but are expressions of what Kristvik calls ‘cultural scripts’. Whereas ethics has focused on the completeness of the information provided, Kristvik plausibly urges for more attention to responsiveness to cultural scripts.

In a way, Nora Engel also studies a form of ‘awkward engagement’. Her study is about the implementation of complex treatments for multi-drug-resistant tuberculosis, a rampant condition in India that poses grave risks to public health which can, according to epidemiologists, only be curtailed by imposing strict treatment compliance on patients. As in Holten’s and Richters’s case study, this universal standard of treatment proved difficult to implement in the everyday life of the patients. Local adaptation of treatment regimes seems unavoidable, but public health officials, in an ‘either / or’ logic, construct this as a threat to their program, some of them going as far as wanting to exclude not completely compliant patients from treatment. Engel argues for abandoning dilemma thinking (so dear to many medical ethicists) and encouraging serious attention for, and study of, local adaptations of treatment regimes.

Gaps of the most various types are the subject of Annemiek Stoopendaal’s paper on fall prevention in the Netherlands. Physical gaps in floors, organizational gaps, mental gaps, all contribute to insufficient prevention of falls in elderly people. But the main gap Stoopendaal discusses is the one between managers and professionals. Fall prevention as such displays a conflict between two central values in ethics: protection versus freedom, and this value conflict is played out both on the professional and the management level. Stoopendaal’s paper shows that it is crucial to study the way abstract value conflicts get translated into different strategies by the actors involved.

It is quite rare for studies in health care ethics to talk about managers except as bad guys. Therefore it is interesting that, next to Annemiek Stoopendaal's paper, the one by Oldenhof and Putters also studies value conflicts that are experienced by operational managers in Dutch health care institutions. Their case is the task of managers to reconcile the values of affordability and client-centeredness through client-based financing schemes such as personalized budgets. Through interviews with managers, they were able to distinguish four modes of dealing with value tensions: balancing values (the standard ethical approach), prioritizing one value over another, compromising between values, and making care gives responsible. This is plausible, but the value of their paper clearly is that ethics needs to take the ethics of managers seriously (and study it).

The paper by Carolien Pronk takes us back from managers to the more common theme of caregivers, but it focuses on an aspect of care that is not very often addressed in the ethics literature: restoring meaning in life for teenage mothers. Even though she speaks of spirituality, the kind of care goals that Pronk talks about have nothing of the 'wooliness' of that concept. Her research is based on interviews and participant observation in a care centre for teenage mothers in Amsterdam. Pronk's is the only paper in this issue that takes the quite classical approach of starting from a theoretical concept: Joan Tronto's notion of 'restoring worlds' as an aim of good care, analysing how this works out in actual care practice. Her paper about 'restoring worlds' deals with a vision that is hardly part of the standard ethical values of care.

Sharon Kaufman's question in her paper on making longevity in United States hospitals, takes up one of the concerns of the symposium that this issue is based on how new health care practices reshape our ethical questions and answers. She argues that a new form of ethical rationality emerges out of three parallel developments related to longevity: the changing of the definition of disease, the technology-driven creation of new health needs, and the financing of relieving these new needs in the continually expanding benefits in the US Medicare system. One of the ethically crucial factors is that the making of longevity is not occurring in some freakish side-show to mainstream health care called enhancement, but that the financing schemes takes into the heart of health care. The fascinating meta-ethical question raised by this paper is of course about the usefulness of ethical debates now, when new possibilities will reconstruct up to the rationality that guides these debates.

The last three papers in the issue return, in a way, to the theme of 'awkward engagement' as it was launched in the paper by Holten and Richter. Their subject, however, is research instead of care practices. The overarching question of these three papers is whether North-American and European criteria for ethical or unethical research can be used for anthropological research everywhere. Unsurprisingly maybe, the answer is 'No', but the loudness differs a bit.

Sjaak van der Geest, in a paper that, with admirable frankness, discusses his own, at least partly unethical, behaviour in research, considers such principles as ethnocentrism and points to the irony of applying allegedly universal principles in a discipline that champions the importance of local variety. After reflecting on the four main ethical principles issued by the American Anthropological Association using his own and

others' scientific work, Van der Geest concludes that these guidelines, even though ethnocentric, leave enough space for researchers to carry out sensitive research, but that other actors in the academic 'powerhouse' misuse them to refuse publication in their journals.

Shahaduz Zaman and Papreen Nahar return to the issue of the universal and the local in a paper about the ethics of research in different health care contexts in Bangladesh. Using a wealth of sometimes hilarious and absurd examples, they show how even the concept of research was hard to convey to their respondents, let alone further ethical demands such as informed consent, confidentiality, etc. Like Van der Geest, they argue that, paradoxically, some degree of 'deception' may be necessary for this type of research to make it ethically acceptable.

The last paper in this issue, by Priscilla Zwanikken and Pauline Oosterhoff, addresses an issue that is less related to ethnocentricity as to what might be called 'methodocentricity': obtaining ethical clearance for a study, usually demands a fully written out and detailed protocol, without any 'gaps' (to return to the title of another contribution). This may be suitable to the methodology of most medical research, such as clinical trials and epidemiological surveys, but it is hardly applicable to the open nature of anthropological research. Demanding a full protocol, therefore, rather thwarts the quality of anthropological research. The authors report a multi-methods research study on the issue of ethical review of social science studies on health care in middle and low income countries, focussing on the establishment and functioning of a review board in the Royal Tropical Institute in Amsterdam. Even though most of the 'users' (sometimes called victims) of the review seemed to be quite positive about what they learned from it, the authors stress the importance of balancing completeness in the description of the study with the necessary flexibility needed in anthropological research.

In their 'teaser' for the symposium that led to this special issue, Willems and Pols argued that empirical studies of how good care takes shape are needed to show the varieties of ways in which goodness gets worked out. They also emphasised that such studies should not start from a preconceived idea about *the* good, "but should be sensitive to the goods that people involved in health care practices find important" (Willems & Pols 2010: 162). Clearly, the papers in this issue show that the built-in ethics of care practices as diverse as they come raise quite different issues from what medical ethics textbooks and even the established journals in the field would seem to suggest. Just as clearly, several contributions make it obvious that anthropological studies stand to win when they explicitly address the ethical issues in the practices they study, but also in the way they study them.

## Note

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