

“Ethics wars”: Reflections on the Antagonism between Bioethicists and Social Science Observers of Biomedicine¹

KLAUS HOEYER

Department of Health Services Research, Institute of Public Health, University of Copenhagen, Øster Farimagsgade 5, Stairway B, Ground Floor, P.O. Box 2099, DK-1014, Copenhagen K, Denmark

(E-mail: k.hoyer@pubhealth.ku.dk)

Abstract. Social scientists often lament the fact that philosophically trained ethicists pay limited attention to the insights they generate. This paper presents an overview of tendencies in sociological and anthropological studies of morality, ethics and bioethics, and suggests that a lack in philosophical interest might be related to a tendency among social scientists to employ either a *deficit model* (social science perspectives accommodate the sense of context that philosophical ethics lacks), a *replacement model* (social scientists have finally found the “right way” of doing ethics), or a *dismissal model* (ethics should be abandoned all together as a misconstrued veil of power). Increased awareness of differences in styles of reasoning and objects of research interest might help to overcome the hostility, and an anthropological project is presented as an invitation to a dialogue informed by awareness of such differences.

Key words: Anthropology, ethics, multi-disciplinarity, policy studies, social science

Introduction

The developments in genetics in general and the Human Genome Project (HUGO) in particular have since the 1990s recast medicine and biomedical research as a field subject to both scholarly and public debate about ethics. Accordingly, funding agencies have sought to stimulate a new field of interdisciplinary research into what has become known as Ethical, Legal, and Social Issues of genetics in North America (ELSI) and Ethical, Legal, and Social Aspects (ELSA) in Europe. In many science journals the various projects conducted with ELSI/ELSA funds are referred to simply as medical ethics or bioethics,² and indeed a great number of legal scholars have been willing to recast themselves as bioethicists (Knoppers, 1999). The “S” in the ELSI/ELSA ambition, however, still seems to make a bad fit for the field, and social scientists still seem reluctant to frame their work as bioethics.

Instead of a flourishing interdisciplinary academic field in which social scientists and philosophically or legally trained bioethicists cross disciplinary boundaries to collaborate and seek inspiration in other styles of reasoning, there seems to be very few cross-references and perhaps even a growing antagonism and disrespect between the majority of the qualitative social scientists and the scholars seeing themselves as bioethicists.³ If we have overcome the science wars, we might now be facing an emerging “ethics wars.” It could be seen as part of a battle for funding and public legitimacy. This might not be the only reason, however, and in this paper the focus is on another dimension of the antagonism, namely the differences in styles of reasoning. The paper argues that part of the reason for the meager collaboration between bioethicists and qualitative social scientists working with moral and ethical aspects of biomedicine might be that the social science contribution tends to be formulated in ways which hamper the impetus for a fruitful dialogue (indeed a similar argument could possibly be made concerning the possible ethical contribution to social science, but the emphasis here is on the social science contribution to the ELSI/ELSA field).

Various approaches in the social sciences tend to present themselves as “finally getting it right”, and such hegemonic claims inevitably impede mutual learning. Many social science studies should have relevance to normative ethics, since their insights emanate from close empirical observations in clinical and research contexts, from siding with patients, and from observations of the ways in which people aspire to conduct moral lives in practice. However, I suggest that most of these social science studies can be seen to employ either (1) a *deficit model* (social science perspectives accommodate the sense of context that bioethics lacks), a *replacement model* (social scientists have found a better way of doing bioethics), or a *dismissal model* (bioethics should be abandoned all together as a misconstrued veil of power). It is hardly surprising if bioethicists do not feel invited to a dialogue. Instead, I argue here that an approach that would facilitate more productive interdisciplinary working relations should involve an awareness and acceptance of the inevitability of multiple forms of reasoning, or what Paul Rabinow (2003) calls heterologoi. In fact, anthropologists and sociologists might even want to learn to reverse the optic and occasionally apply a philosophical vocabulary to describing selected social science positions.

The antagonism between different approaches to studying “moral issues” might reflect the fact that different disciplines seek to understand dissimilar phenomena for different reasons, while nonetheless using similar vocabularies. In this paper I offer a clarification of some dominant types of study in the qualitative social sciences, notably anthropology,

without any claim of comprehensiveness. The intent is to help identify levels of disagreement amongst social scientists, because such awareness is a precondition for fruitful interchanges with bioethicists using the same concepts in other ways. Beginning with classical and more recent studies of “ethics,” “morality,” and “moral” as broad social phenomena, an outline of the social science studies of bioethics follows, before the various approaches are summed up in a simplified schematic overview. In the final section of the paper, I outline the research project that prompted my reflection on the relationship among anthropology, sociology, and ethics. For some years I have studied the ethics policy developed by a start-up genomics company in northern Sweden. This has given rise to some reflections on how different forms of inquiry must be viewed as complementary rather than as superior or inferior. This indicates a need to embrace hetero-logoi, and the conclusion develops these reflections.

Generally social scientists mean something different with the words “moral,” “morality,” and “ethics” than do moral philosophers; the terms are even used differently within social science debates. A concept like “moral”, for example, is used both as an adjective and a noun. In the following overview, the use of the concepts follows that of the discussed authors rather than predefined categories. However, to discriminate between dominant trends, I draw distinctions between studies working with concepts of “ethics,” “moral,” and “morality” which are primarily *ontological* (aspiring to understand what ethics is), primarily *epistemological* (using the concept to understand something else), and primarily *discursive* (taking ethics to mean anything but studies of the power effect of discourses on ethics).⁴ We begin with studies using ontological concepts.

Classical and Recent Studies of Ethics, Morality and the Moral

During the early days of the field, the study of the moral was central to sociology. Emile Durkheim, for example, deliberately wanted to reclaim the study of morality from philosophy and repeatedly stated that the moral is a social fact that should be studied as such (Durkheim, 1957, 1979b). He believed to find in morality the glue of social structures and included “the moral” among the objects of a positivist sociology (Durkheim, 1973). In particular, Durkheim argued that moral norms were constitutive of a professional identity and spurred a number of studies of the morality of professional groups. Interesting studies of the professional identity of medical doctors and medical decision-making emanate from this tradition, giving empirical weight to our understanding

of the daily procedures of hospitals (Anspach, 1993; Bosk, 1979). However, the Durkheimian interest in morality as a social fact had limited impact beyond his time, and with the hermeneutic turn in anthropology (from the study of facts to the study of people and their perceptions and experiences), his positivist image became more of a bogey than an intellectual inspiration. Accordingly, there have been only a few attempts at revitalizing the study of moral and ethics (Edel and Edel, 1959; Jackson, 1982a, b; Read, 1955).

The case for a descriptive study of ethics had been suggested also by another strain of theory stimulated by the last essay of Marcel Mauss (1985), Durkheim's nephew. In this essay, Mauss endeavored to understand the development of the Western notion of self. He showed the historical and cultural specificity of the concept of *person*, which is central to the notion of autonomy. Clifford Geertz, in his seminal book *The Interpretation of Cultures* (1973), made a synchronic analysis of the same topic; but it was with the work of Carrithers et al. (1985) that the Maussian study of the notion of personhood was successfully launched as an anthropological take on issues central to philosophical ethics. This work carefully related the comparative descriptions with the philosophical queries and laid out new questions to be probed by both disciplines. The subsequent two decades have seen an increased use of philosophical arguments in the anthropological understanding of the nature of moral problems, not least from phenomenologically grounded social scientists (see e.g., Jackson, 1998, 2002). The work of Alfred Schutz and his pupils has had some impact in North America and been used by both social scientists and ethicists, and similarly the work of Maurice Merleau-Ponty has given rise to fertile inter-disciplinary studies embracing moral life-worlds as part of their ontology. Still, the anthropological inclination to compare cultures has remained at odds with dominant strains of moral philosophy, as the former seems inevitably imbued with relativism while the latter tends to aspire to develop explanations of moral truth that transcend culture-based norms (Geertz, 2000; Rabinow, 1983).

Debates about the relationship between structure and agency have been central to the study of moralities and different theorists have argued that moral capability emanates from either societal structures (as Durkheim held), or reside in individuals (Rapport, 1997). Lately, Signe Howell has suggested an ethnography of moralities (Howell, 1997), which seems to renew Durkheim's notion of the moral as a social fact, though it challenges the image of "the glue of social structures" both methodologically and theoretically. Whereas Michael Jackson and Zygmunt Bauman had already made ambiguity central to the anthropological understanding of moral (Bauman, 1994; Jackson, 1982a), Howell suggests

working explicitly with dilemmas; that is, to study morality through the moral reasoning in situations where values diverge and choices have to be made. Howell challenges the positivist structural framework of the Durkheimian tradition, as she suggests talking of moralities as constantly emerging and in flux. There is, however, a tendency to be somewhat unfair in the description of Durkheim. Though emphasizing a structural level, he did not see the moral as a fully static phenomenon. On the contrary, he stated that “the moral ideal...is alive, constantly changing and evolving. The future will have a different ideal from that which obtains now” (Durkheim, 1979a: 81).

The question of structure versus agency relates to the notion of choice. This notion is central to James Laidlaw’s recent contribution to the social study of ethics (Laidlaw, 2002). Laidlaw draws on work by Friedrich Nietzsche and Michel Foucault and makes a distinction between the moral as social norm and ethics as the practice of self, i.e., the ways in which a person uses his or her freedom to choose. He seeks to denaturalize our understanding of what is “moral” as the identification of good and evil, and (re-)establish ethics as a comparative field of study, that is, the study of how we execute freedom differently. Laidlaw draws on Foucault, who suggests focusing on four aspects deserving attention in the comparative study of ethics (Foucault, 1986, 1992, 1997): (1) *Ethical substance* (How and why does something become an ethical problem?), (2) *mode of subjection* (Which form does the discursive environment for the ethical substance take; is it, e.g., religious, scientific or aesthetic?), (3) *self-forming activity* (What can you do to act ethically, e.g., pray or work hard?), (4) *teleology* (What does the subject aspire to, e.g., an afterlife or a career?). By studying these features of how humans conduct their lives, the analyst can come to understand other forms of moral reasoning and further critical reflections.

It is noteworthy that despite Foucault having worked within an explicitly anti-essentialist tradition, and in spite of having distanced himself from any theorizing on the “human condition” (Dreyfus and Rabinow, 1983; Foucault, 1994), Foucault at the end of his authorship gets as close as ever to saying something about a basic human condition: the freedom to choose. The point is, however, that what is made the object of choice is never voluntarily decided; every choice is presupposed by other choices and creates yet other choices. As such, the “practice of self” is constantly emerging, and is not a self-generating basic unity from which structures emanate. There is no doer behind the doing, no chooser behind the choice. There is no truly transcendental ego in the sense discussed by Jean-Paul Sartre (1977). Nevertheless, Foucault and Laidlaw direct their attention to ethics as an object of study and employ the

concept in an almost ontological sense, i.e., as the name of something they want to know more about (though semantically speaking, both would probably describe their concepts from a nominalist perspective).

Others have focused on values rather than morality (e.g., Kroeber, 1952:136). Lately the concept of value has been re-conceptualized by David Graeber with the attempt of integrating diverse meanings of the word value (economic, moral and semantic value) as interdependent aspects of any action by motivated agents (Graeber, 2001, see also Waldby, 2000). Graeber argues that value is what we desire and work for and that it is revealed in action, not through deliberation. He aspires to overcome what can be described as a logocentrism in Western conceptions of value and ethics, and attunes the analyst to issues at stake at a nonverbal level for various actors. This move is important in seeking to understand emotions that evade articulation for various reasons. Fredrik Barth follows Graeber in his attempt to attune the analyst to tacit human practices embodying moral worth, but he adds a methodological challenge (Barth, 1993): if we observe only what people aspire to with their acts, we do not capture their own understanding of what constitutes moral concerns. Conversely, we cannot rely on people's own articulation of values because the values informing their conduct of life tend to be so much taken for granted that they would not be considered as worth mentioning. Societies where, for example, sharing is embedded in social practice, do not discuss this as an ideal, whereas societies with strong commitments to private property tend to do so (Barth, 1993).

Values are the object of knowledge for both Graeber and Barth; they work with an ontological concept. However, when Barth and Graeber highlight the values revealed through action, they align everything which is desired with value. This makes it very difficult to argue that something for some reason is without *moral* value. The notion of value and morality could in this framework be replaced by a notion of preference, and in this sense moral value is in fact subordinate to a game of power; the power to pursue one's preferences. This approach is rarely applauded by moral philosophers aspiring to develop arguments as to why one should prefer one act to another.

Moral Economies and Exchange Studies: Epistemological Concepts of the Moral

Durkheim's contemporary, Max Weber, also worked on moral issues, but whereas Durkheim used the concept of morality primarily in the

ontological sense (as the name of a thing we should investigate), Weber predominantly used the concept in an epistemological sense (i.e., as an aid in our interpretation of other social phenomena). Weber's well-known and influential book on the Protestant ethic demonstrated how a concern with how one ought to act could interact with the emergence of certain types of economic systems (Weber, 1992). This approach to ethics has proven itself immensely influential in the social sciences. Ethics, ethos, the moral, morality, and value have become concepts that are primarily used to understand a specific aspect of something else, and not the object of study as such (see e.g., Bateson, 1958).

Of particular importance to recent studies of ethical, legal and social aspects of biomedicine has been the anthropological study of exchange systems. A central essay is *The Gift* by Marcel Mauss (2000), which laid out a mode of analysis for studies of exchange systems, and emphasized the pre-existence of relations between exchanging parties: nobody exchanges anything without a pre-existing idea about the sort of obligations it would incur on the respective parties (Frow, 1997).⁵ Inspired by this work, substantialists have argued that economies are structured by culture and moral values (Sahlins, 1972), as in the so-called "moral economy studies" (Scott, 1976). More actor-oriented theorists (the so-called formalists) have argued that economies emanate from self-maximizing, rational individuals (Barth, 1967). Igor Kopytoff and Arjun Appadurai have transcended the divide between substantialism and formalism by looking at the meanings produced in specific culturally construed forms of exchange, i.e., by looking at the meaning produced in specific exchange situations rather than the construction of exchange systems in general (Appadurai, 1986; Ferguson, 1988; Kopytoff, 1986). These studies have implications for the analysis of medical exchange systems, where the meanings ascribed to, for example, organs and tissue samples, can be shown to change relative to different stakeholders (Hoeyer, 2004). Mauss has also inspired some social policy studies, in particular Richard Titmuss' (1997) famous argument for a gift relationship in systems for blood donation.

What unites all these studies is the analysis of moral value as an aspect of economic life, to use it to understand concrete arrangements of exchanges, and to reinstate culture in economics. The central lessons of this type of economic anthropology are that exchanges of goods are culturally embedded, that there is a continuum between gift and market economies, and that gifting is informed by cultural norms and expectations.

Studies of Normative Medical Ethics

Strangely enough, the studies of moralities described above have had only marginal impact upon the social study of *bioethics*. Recent studies assessing the contributions from the social sciences to bioethics do not even mention Durkheim (Hedgecoe, 2004; Muller, 1994; Spallone et al., 2000; Zussman, 2000), even when setting out to give a general review of the sociological perspectives taken on ethical issues (Haimes, 2002). This can probably be related to the ways in which these scholars have come to address bioethical concerns. The social scientific commentary on bioethics can be seen to fall in two main corpuses of work: one emanating from medical anthropology and sociology, and the other emanating from studies of power; neither of these is particularly closely affiliated with Durkheimian sociology.

In the studies emanating from medical anthropology and sociology, the social scientists typically take a normative point of departure in the idea that patients constitute a weak, vulnerable, and varied group in relation to medical professionals, who are more powerful, active, and homogenous (Gabe et al., 1991). Accordingly, many anthropologists and sociologists use the analytical distinction between patients' complex and ambiguous emotional experience of illness, and unequivocal, rationalist biomedical definitions of disease, to frame their contribution to bioethics (Kleinman, 1995, 1999). In parallel to the illness/disease distinction, they distinguish between patients' complex moral worlds and bioethical pretensions of universal clarity (see e.g., Gammeltoft, 2001; Kaufert and O'Neil, 1991; Nelson, 2000b). The most compelling studies identify in mainstream bioethics a reduction of moral complexity and an inability to address the actual social contexts in which moral choices have to be made (most forcefully argued in Alderson, 1993; Anspach, 1993; Bosk, 1992, 1999; Gorden and Paci, 1997; Kaufman, 1997; Zussman, 1992). Some bioethicists have identified similar shortcomings with respect to social context in medical ethics (Hoffmaster, 1992, 1994; Holm, 1996). This has spurred studies which not only comment on bioethics, but aspire to a new way of doing it (see e.g., Beeson and Doksum, 2001; Borneman, 2001; Joralemon, 2000; Kaufman, 2001). Indeed a number of sociologists commenting on the relationship between bioethics and sociology claim that their contribution should not be regarded as simply "adding the facts to normative judgment," but must be acknowledged as a more fruitful, theoretically informed approach to bioethical issues (Haimes, 2002; Nelson, 2000a).

The previous section introduced a distinction between ontological and epistemological concepts, but many of the studies of *bio-ethics* seem to

fall in neither camp. Instead, they tend to use the concept of ethics in what I term a *discursive* sense. When used as a discursive concept, “ethics” is not taken to mean anything; rather it is the implications of “ethics talk” that are the objects of analysis. In particular, this seems to be the approach used when the analyst focuses on the introduction of bioethical regulation. If we review the studies critiquing bioethics from the perspective of medical anthropology or sociology, some of them can be seen to employ an epistemological concept of the moral, because they primarily analyze the social structure of the clinical setting or the doctor/patient interaction. Most of them, however, combine more or less intentionally ontological and epistemological senses of the moral, with discursive senses, in as far as they seem to work with ontological notions of patients’ local moral worlds, while using the concept of ethics in the discursive sense to describe the work of medical ethicists as a game of power.

A purely discursive concept of ethics is employed in that corpus of work that takes its inspiration mainly in political anthropology and sociology. Ethics is here seen primarily as a political technology and the focus is on the political implications of bioethical discourse and institutions. The proliferation of ethics is viewed as an expression of particular interests, and analyzed as negotiations between unequal actors (Corrigan, 2003; Fortun, 2001; Novas and Rose, 2004; Pálsson, 2002; Pálsson and Harðardóttir, 2002; Pálsson and Rabinow, 2004; Scocozza, 1994; Whitt, 1999). These scholars have produced important insights into the power effect of phenomena referred to as “ethical”, not least Nikolas Rose, who – with inspiration from Foucault – talks of a “new game of power [that] operates in a field one could term *ethico-politics*” (Rose, 1999: 188). This field functions through “technologies of *responsibilization*” (Rose, 1999: 74), and what might be presented as increased freedom is also a way of enrolling citizens in government through an obligation to make choices which will have to be informed by experts (Rose, 1999: 83). This perspective has direct relevance for an analysis of the practical implications of, for example, the informed consent requirement often debated in normative bioethics. Though mostly discussed as an expression of respect for the individual, the research participants might feel a responsibility impinge on them; litigation cases provide relevant examples. Also, some of the studies emanating from medical anthropology have come to see ethics as a technology of power which serves unjust systems of exchange, particularly in the case of organ transplantations (Scheper-Hughes, 2000, 2001, 2002; Sharp, 2000). These studies show how discourses of autonomy have been used to further the rights of wealthy healthcare consumers

at the expense of marginalized groups who come to view their bodies as resources for the family economy (Das, 2000).

Some of the studies in this tradition, however, see in morality nothing but personal or institutional interests. Accordingly, they could be described from a philosophical perspective as a form of inadequately argued emotivism; like Graeber and Barth, they reduce the scope of the moral to personal preferences. Though pretending to take a merely descriptive stance, these scholars in fact advance a moral philosophical position without realizing the need to justify it. While accusing moral philosophy of unjustified universal pretensions, these social scientists endorse a position in the philosophical framework which does not acknowledge any other form of moral reasoning, and they imbue the concept "moral" with one specific meaning (i.e., preference) that rules out other understandings. Existentialist philosophers have taken the argument further and suggested that this type of position, where everything is just preferences (a position they term aesthetic, see Beauvoir, 2000: 73–77), is fundamentally irresponsible. However, this need not be an argument against this type of study *per se*, because this approach to ethical discourse has been a methodological necessity in studies that have generated important insights on the political implications of such discourses, (e.g., Black, 1998; Kelly, 2003; Pálsson and Rabinow, 2004; Whitt, 1999). Nevertheless, the criticism provides reason for not letting such studies stand alone.

Social scientific work on bioethics has had limited success in engaging in dialogue with people identifying themselves as bioethicists. This probably relates the fact that most of the studies just described embody either a *deficit model*, a *replacement model*, or a *dismissal model*, as outlined in Table 1.

These studies take the form of criticism of ethics rather than forming a contribution to ethics. Furthermore, they have tended to work with a black box notion of bioethics as a monolithic, homogenous entity, a *fait accompli* striking down on local moral worlds. There has been little awareness on the part of social scientists of the influence (and impact) on bioethics of feminist ethics (Walker, 1998), pragmatic ethics (Fesmire, 2003; McGee, 2003), phenomenological ethics (Zaner, 1993), neo-virtue ethics (Castoradis, 1997; MacIntyre, 1984) contextualist ethics (Hoffmaster, 1994, 2001) and other ethical traditions that work with understandings of moral problems in ways more closely affiliated with social scientific approaches. Thus it is hardly surprising if philosophical bioethicists have paid little attention to the criticisms of social scientists, particularly when these critiques appear to embody "straw man" representations of bioethics, and are made by people unaware of the

Table 1. Dominant trends in sociological and anthropological contributions to bioethics.

| Type of study | Position implied in argument | Examples |
|----------------------------|---|---|
| <i>A deficit model</i> | Social science perspectives have the sense of context that bioethics lacks. | Alderson (1993); Anspach (1993); Bosk (1992, 1999); Csordas (2000); Gorden and Paci (1997); Kaufman (1997); Nelson (2000b); Wexler (2000) |
| <i>A replacement model</i> | Social scientists have finally found the “right way” of doing bioethics. | Beeson and Doksum (2001); Borneman (2001); Joralemon (2000); Kaufman (2001) |
| <i>A dismissal model</i> | Bioethics is a misconstrued veil of power and should be abandoned. | Amit (2000); Bourgois (1991); Harrison (1991); Nader (1976); Scheper-Hughes (2001, 2002) |

philosophical implications of their own endeavor. However exciting we might find the respective studies, the reluctance to scrutinize ones own practice and the lack of respect for philosophical discourses seem to have generated an emerging “ethics war” between philosophers and bioethicists on the one side, and social scientists on the other.

Summing up the Various Types of Social Scientific Study of Ethics and Moral

The different positions discussed above are organized in Table 2 to facilitate an overview. Category A includes studies seeking to develop ways of analyzing ethics and morality as objects of study in their own right; Category B comprises studies where ethics and morality are only concepts to help us understand something else (e.g., exchange systems); and Category C lists studies inspired by discourse analysis focusing on ethics as a technology of power. The arrangement in categories illustrates how studies presumably deliberating the same topic (ethics and morality), in fact have different objects of analysis and employ the same words but with different understandings.

Of course, some studies transcend these tendencies (Franklin, 2003; Lock, 2001, 2002; Rapp, 2003) and embrace an understanding of morality generated in the tradition of type A and B studies, though belonging to category C in as far as they investigate ethics, not as a defined analytical object, but as an emerging social phenomenon carrying different meanings for different people. The merit of this type of approach is to assign the concept of power no greater ontology than the concept of morality,

Table 2. Approaches to the study of ethics and morality

| Type of question | Concept | Key issues | Examples |
|--|--|---|--|
| A. What is the nature of the moral? | <i>Ontological</i> concept (the name of the object of analysis) | Does the moral spring from society or individual The role of philosophy Relativism Freedom of choice/practices of self | Barth (1993); Durkheim (1957, 1973, (1979b); Edel and Edel (1959); Foucault (1986, 1992); Geertz (1973); Graeber (2001); Howell (1997); Jackson (1982a, b, 1998); Laidlaw (2002); Mauss (1985); Read (1955) Bateson (1958); Kopytoff (1986); Mauss (2000); Sahlins (1972); Scott (1976); Titmuss (1997); Weber (1992) |
| B. How do surrounding structures, forms of organization, knowledge forms and the execution of power interact with the moral? | <i>Epistemological</i> concept (an aid in the analysis of something else) | Substantialism vs. formalism Moral economy Gift relationships | |
| C. What happens when people talk about the moral, morality, and ethics – and which forms of social practice are termed “moral” and “ethical” issues? | <i>Discursive</i> concept (a second order perspective on a floating signifier) | Complex local moral worlds vs. universal reductionist ethics Ethics as a technology of power | Kleinman (1999); Lock (2002); Rabinow (1999); Rapp (2003); Rose (1999); Scheper-Hughes (2002); Shore and Wright (1999); Strathern (2000); Whitt (1999) |

and thus to avoid claiming that the social descriptions of, for example, political negotiations of ethical issues are somehow “more real” than, for instance, moral reasoning or the ability to care.

In my own work, which I now briefly outline, this approach has been the explicit objective. The project represents not the “right way” of approaching ethical issues, but a personal attempt at finding an anthropological task complementary to the one fulfilled by normative bioethics. I describe it here for three reasons: firstly as an example, primarily aimed at social scientists, of an analysis that explores power strategies at work in the development of ethics policies without giving the concept of power ontological primacy over the concept of morality; i.e., avoids an analysis where reference to moral issues appears to be naïve at best, “false consciousnesses” at worst. If we want to preserve room for normative critique (which indeed is the aim of most social science), it is important to realize that emotivism is not the only logical outcome of social science critique, and thus to acknowledge moral theory to be as valid as theories of power. Secondly, the case study serves as an example to bioethicists of a type of study which does not pretend to stand on its own as an all-encompassing or comprehensive analysis, but nonetheless offers a contribution that cannot be simply replaced by philosophical deliberation. Thirdly, the subsequent discussion of the study exemplifies how all relevant questions cannot be contained in one approach; there is a need to accept other modes of inquiry than one’s own.

A Case Study: UmanGenomics and the Study of Ethics as Policy

This example, taken from an anthropological study carried out in Sweden that began in the summer of 2000, explores the ethics policy of a start-up genomics company, UmanGenomics, which is based in the town of Umeå. This ethics policy, which was acclaimed in prestigious journals such as *Nature* (Abbott, 1999) and *Science* (Nilsson and Rose, 1999), was believed to provide a concrete example of how to solve the ethical problems of commercial genetic research on public biobanks, an issue that has been substantially debated since the case of deCODE Genetics in Iceland. The main feature of the UmanGenomics policy was the introduction of informed consent to the DNA collection and participation in biobanks; informed consent was expected to be implemented by nurses collecting the samples, and to present potential donors with new choices.

As ethics was here instantiated in the form of a policy, I have found inspiration in the field of anthropology of policy to “study through”

(Shore and Wright, 1997), that is, to direct research questions towards an understanding of the development of the policy as it evolves at three levels:

- (1) Policymakers: *How the policy takes shape*: Who names and frames the issues the policy will address? What becomes the object of regulation?
- (2) Policy workers: *How the policy becomes entrenched in social practice*: How does it affect the work of the people expected to procure informed consent from donors, in this case nurses? Do they know of the policy at all? How do they handle the demands imposed on them?
- (3) Target group: *What are the social implications of the policy for the target group*, i.e., potential donors?

The methodological principle has been to move between these levels and mirror the different forms of framings of problems expressed at the three levels in each other. This has necessitated an understanding of moral problematizations as expressed through speech acts as well as non-verbal action. Drawing on the insights of the studies of both Categories A and B described above (Table 2), a notion of moral interest has been developed to grasp what is at stake for people in different situations, and to make a comparison feasible. This comparison has exposed moral problems not included in the policy, and made it possible to assess the implications of the ethics policy of informed consent as a clinical practice.

Over the course of more than 80 years of medical practice and research, approximately 60 million samples have been collected and stored in Swedish hospitals from a population of just 8.5 million inhabitants. It is only recently these samples have been presented as ethically problematic. By studying the policymaking related to tissue collection and banking, it has been possible to identify four ways of naming and framing ethical issues which have established a problem that a policy on informed consent was seen to solve: (1) Blood samples were presented as similar to living persons, i.e., no difference was seen between using a blood sample and a living body for research; (2) the problem was construed as a conflict between the individual and society, where the integrity of the donor was supposed to be at odds with the interests of society; (3) the provision of information to individuals was put forward as a solution to safeguarding individual autonomy; and (4) better ethics was conflated with providing more information.

The point is that not all these propositions are shared by the policy workers (in particular the nurses procuring informed consent) and the policy's target group, the potential donors. In my study, I have observed and interviewed 57 potential donors as they were invited to participate in

the biobank collection, as described in more detail elsewhere (Hoeyer, 2002, 2003, 2005). In contrast to the four problematizations at the policymaking level, I found that (1) Some donors do not find blood samples particularly important; they are much more concerned about ensuring appropriate access to phenotypic information, a concern that the policy does not address although a questionnaire is submitted along with the blood sample; (2) Most donors do not see their own interests as divergent from those of the surrounding society which in fact is why they often donate in the first place; (3) Few donors actually read or care about the information offered in the informed consent process. They instead request political control over research and express concern about assuming personal responsibility for the research oversight; (4) Finally, some donors find more information tedious and burdensome, rather than ensuring “better ethics”. One man who wanted to sign his consent form but had not cared to read it, said, when a nurse insisted on informing him, “Are you going to force me [to read it]?”

It is not that donors see no moral problems in commercial genetic research, but they raise other moral concerns that have more to do with the equal distribution of research results, eugenic uses of science, etc. (Hoeyer, 2004). More importantly, these concerns can hardly be addressed through individual informed consent! Perhaps this is why less than 4% of donors responding to a survey on the topic thought that the most important issue in biobank research was whether they were personally informed (Hoeyer et al., 2004).

In sum, a particular naming and framing of what constitutes ethical concerns has taken place in relation to UmanGenomics and this Swedish biobank. This fixation of legitimate moral concerns is to some extent inconsistent with the concerns of the people for whom and with whom the policy was intended to work. The policy has been an apt political “solution,” but an inadequate representation of the concerns of the donating public. The idea of a solution is central to all policy work: policies have to present themselves as solutions, even when problems are only vaguely defined. But what then is the role of anthropology in this setting?

Discussion: Complementary Tasks and the Inevitability of Hetero-logoi

First, there might be a role for anthropology in understanding the constraints on analytical thought produced by policymaking. This necessitates an observer’s position (what could be termed a second order perspective) with no obligation to contribute to policymaking (interaction

from a first order perspective). A second order perspective can be employed by bioethicists as well as social scientists (cf. Wolpe and McGee, 2003). The proposition offered here is that when bioethics is supposed to deliver practical guidelines (policies), only those problems with manageable solutions will tend to be addressed (Weiss, 1986). Renée Fox and Judith Swazey contend that the “advisory role to decision-makers has reinforced the cognitive predisposition of bioethics to distil the complexity and uncertainty, the dilemmas and the tragedy out of the situation they analyze” (1984: 356). This makes informed consent a particularly apt solution, and might contribute to an understanding of the recent emphasis on consent as an expression of respect for autonomy in the branches of bioethics most eager to influence the conduct of medical practice.

There were bioethicists involved in the development of the ethics policy of UmanGenomics, just as there are social scientists involved in the ethics policies of the HapMap Project (The International HapMap Consortium, 2004) and UK Biobank (Tutton et al., 2004). However, the disciplinary affiliation might have less importance than the position from which discussions about ethics are taken: do these positions necessitate practical guidelines (i.e., “solutions”) in the form of policies or is the observer free to identify problems that the relevant decision-makers might not find particularly appealing or manageable?

My study of UmanGenomics’ ethics policy was directed by a search for subjugated moral positions, i.e., the moral problems not addressed by the ethics policy. This task resonates with the work of feminist ethicists such as Margaret Urban Walker (1998). As such, it rests on a moral framework for which subjugated moral positions are deemed important and worth uncovering. But, unlike the ethicist position represented by Walker, the anthropological mode of reasoning presents no argument as to why these positions should be uncovered. If the type of study presented here allows us to see that a series of moral concerns are not addressed by a policy – while our theoretical understanding of policies also indicates that no policy will ever address all concerns to the satisfaction of all stakeholders – how are we then to choose which concerns to deal with and which to ignore?

The making of an answer to this type of question necessitates a mode of reasoning different from the anthropological analysis of policies. The point is not to reinstate strong distinctions between description and prescription (between “is” and “ought”) and pay tribute to the notion of the naturalistic fallacy. It is, rather, to note the divergence in research interests between seeking to understand how a policy comes about (which positions it marginalizes, what implications it has, and for whom), and

seeking to provide an argument for why one should respect one position at the expense of another. The democratic ethos implied in the anthropological search for subjugated moral positions rests on a methodologically necessary relativism, where all moral positions in principle have equal worth. This approach can generate new questions such as: Why is the governance of biobanks reduced to an informed consent requirement that few donors use? How do we safeguard donors if a consent requirement does not serve that function in practice? Is it possible to work into the research structure ways of addressing the larger issues of particular concern to donors, e.g., equal distribution of research results, forestalling eugenic uses of science, etc.? The anthropological mode of reasoning is poorly equipped, however, for answering these questions or for providing weighty arguments for or against seeking answers to some of these questions rather than others.

In sum, with my work I have not tried to add to the number of solutions as such. Rather, I have suggested that there is a role for anthropology in recasting the problems. This task involves probing the logic of the existing solutions, questioning the ability of current solutions to address the problems already launched, giving voice to concerns otherwise marginalized, and reconsidering whether other problems might be demanding attention.

Conclusions

It would be naïve to assume that everybody at some point would come to agree on which questions to ask or anticipate agreement on the possible answers (Gjerris, 2003). Disagreement about the criteria for arguments, evidence, and relevance are bound to persist. With the notion of heterologoi, Paul Rabinow (2003) alerts us to the importance of using this fact productively in order to engage fruitfully with other forms of reasoning, rather than simply assuming that it is just a matter of time before others will see the light that has presumably dawned on oneself. While this might at a first glance resemble relativism, it is basically a pragmatic starting point for critical reflectivity about the knowledge project with which one is engaged. Through acceptance of the fact that other traditions work with different criteria, research questions, and modes of reasoning, and that no form of reasoning will ever be able to embrace all questions or generate all answers, it is possible to engage more productively with other knowledge traditions and see if they can alert one to blind spots in one's own research practice. It is not a matter of expecting a complete fusion of methods, the right level of eclecticism, or a grand theory encompassing all

the different insights. On the contrary, the point is to relinquish this project and assume a more modest mode of inquiry embracing reflexivity concerning its own limitations.

The social sciences generate many important insights which could develop and inform normative ethical reasoning. The social scientific mode of inquiry can, for example, test philosophical assumptions about people's interests, scrutinize the practical implications of implementing particular ethical recommendations, and generate new questions of relevance to ethical deliberation. Studies seeking to understand morality as a basic feature of human lives can challenge or substantiate philosophical theories. Studies of exchange systems might alert bioethicists to the social production of systems of gifting (challenging notions of altruism as well as distinctions between gift and commodity) and provide an improved empirical understanding of situations in which bioethicists may want to intervene. Studies of the discursive type can, if not read as a dismissal of all types of ethics, stimulate reflection on the practical implications of offering normative guidance to policymaking. Conversely, increased awareness of philosophy and ethical debate could help many social scientists to reflect on their tendency to reduce morality to mere preferences, thereby depriving the former of some of the meanings central to the way we understand discussions about moral and ethical problems as a corrective to our preferences. Therefore, it would be fruitful to enhance the dialogue, not between bioethicists and social scientists already widely sharing a research agenda (as in the case of the contextualist studies which in fact resemble many of the social science studies that I categorized as belonging to the deficit model), but between scholars wanting to research fundamentally different questions with fundamentally different approaches. If we can avoid claiming that we "finally got it right", we might also better understand how to use the questions pursued by other researchers to understand the limitations of our own knowledge projects.

The vision offered here is therefore that each practitioner should do what he or she does best, while remain willing to learn from others about the blind spots of his or her knowledge projects. This might turn the battlefields of the ethics wars into a productive laboratory for probing the existing notions of what constitute the current dangers and the best solutions.

Notes

1. This paper was first presented at the 4S/EASST Conference in Paris, August 25–28, 2004 in a panel co-convened with Richard Tutton, who came up with "Ethics Wars"

- as the appropriate title for the state of affairs we wanted to discuss. Bryn William-Jones contributed to the panel and provided detailed and very useful comments to the paper. The project on which the article reports was financially supported by the Swedish Ethics in Healthcare Programme (Grant 2000/56) and the Danish Social Science Research Council (Grant 24-03-0219).
2. As will be discussed below there is no agreement on what the various terms cover. In the following I will use the broad term “bioethics” to denote the various approaches to normative deliberation on issues relating to biomedical research, healthcare and the health services, and ignore the uses of the term in studies of e.g., agricultural research etc.
 3. There is a contest over disciplinary identities and no agreement on self-labelling. In the following I use the term “bioethicist” to denote scholars working with explicit normative intent irrespective of their disciplinary background in moral philosophy, various forms of applied ethics, or medical ethics, and I focus on the relationship between qualitative social science perspectives and bioethics, thus leaving aside the legal perspectives which seem to make a much better fit with bioethics. Also, as noted below, there are some bioethicists willing to embrace social science perspectives and some social scientists willing to view their work as forms of ethics. The focus in this paper, however, remains on the reasons for limited dialogue.
 4. The distinction between ontological and epistemological concepts is adapted from Kirsten Hastrup (2002), while the term discursive concepts has been added by the author.
 5. It has been pointed out by Sigaud that *The Gift* was interpreted by his contemporaries as of relevance to the study of primitive law; the establishment of duties (Sigaud, 2002). The reading of the essay as concerning exchange stems from the 1960s, but is the most prevalent today and the type of reading that I have applied.

References

- Abbott, A. (1999). Sweden Sets Ethical Standards for Use of Genetic “Biobanks.” *Nature* 400: 3.
- Alderson, P. (1993). *Children’s Consent to Surgery*. Buckingham: Open University Press.
- Amit, V. (2000). The University as Panopticon. Moral Claims and Attacks on Academic Freedom. In *Audit Cultures. Anthropological Studies in Accountability, Ethics and the Academy*. Ed. M. Strathern. London: Routledge.
- Anspach, R.R. (1993). *Deciding Who Lives. Fateful Choices in the Intensive-Care Nursery*. Berkeley: University of California Press.
- Appadurai, A. (1986). Introduction: Commodities and the Politics of Value. In *The Social Life of Things. Commodities in Cultural Perspective*. Ed. A. Appadurai. Cambridge: Cambridge University Press.
- Barth, F. (1967). Economic Spheres in Dafur. In *Themes in Economic Anthropology*. Ed. R. Firth. London: Tavistock.
- Barth, F. (1993). Are Values Real? The Enigma of Naturalism in the Anthropological Imputation of Values. In *The Origin of Values*. Ed. M. Hechter. New York: Aldine de Gruyter.
- Bateson, G. (1958). *Naven. The Culture of the Iatmul People of New Guinea as Revealed through a Study of the “Naven” Ceremonial*. Stanford: Stanford University Press.
- Bauman, Z. (1994). Morality without Ethics. *Theory, Culture and Society* 11: 1–34.

- Beauvoir, S. (2000). *The Ethics of Ambiguity*. Secaucus: Citadel Press.
- Beeson, D. & Doksum, T. (2001). Family Values and Resistance to Genetic Testing. In *Bioethics in Social Context*. Ed. B. Hoffmaster. Philadelphia: Temple University Press.
- Black, J. (1998). Regulation as Facilitation: Negotiating the Genetic Revolution. *The Modern Law Review* 61: 621–660.
- Borneman, J. (2001). Caring and Being Cared For: Displacing Marriage, Kinship, Gender and Sexuality. In *The Ethics of Kinship. Ethnographic Inquiries*. Ed. J. Faubion.. Oxford: Rowman and Littlefield.
- Bosk, C. (1979). *Forgive and Remember. Managing Medical Failure*. London: University of Chicago Press.
- Bosk, C. (1992). *All God's Mistakes. Genetic Counseling in a Pediatric Hospital*. London: University of Chicago Press.
- Bosk, C. (1999). Professional Ethicist Available: Logical, Secular, Friendly. *Dædalus* 128: 47–68.
- Bourgois, P. (1991). Confronting the Ethics of Ethnography: Lessons from Fieldwork in Central America. In *Decolonizing Anthropology. Moving Toward and Anthology for Liberation*. Ed. F.V. Harrison. Arlington, USA: Association of Black Anthropologists/AAA.
- Carrithers, M., Collins, A. and Lukes S. (Eds.) (1985). *The Category of the Person. Anthropology, Philosophy, History*. Cambridge: Cambridge University Press.
- Castoradis, C. (1997). *Phusis* and Autonomy. In *World in Fragments. Writings on Politics, Society, Psychoanalysis, and the Imagination*. Ed. D.A. Curtis. Stanford: Stanford University Press.
- Corrigan, O. (2003). Empty Ethics: The Problem with Informed Consent. *The Sociology of Health and Illness* 25: 768–792.
- Csordas, T.J. (2000). Computerized Cadavers: Shades of Being and Respresentation in Virtual Reality. In *Biotechnology and Culture. Bodies, Anxieties, Ethics*. Ed. P. Brodwin. Bloomington: Indiana University Press.
- Das, V. (2000). The Practice of Organ Transplants: Networks, Documents, Translations. In *Living and Working with the New Medical Technologies. Intersections of Inquiry*. Eds. M. Lock, A. Young and A. Cambrosio. Cambridge: Cambridge University Press.
- Dreyfus, H. & Rabinow, P. (1983). *Michel Foucault. Beyond Structuralism and Hermeneutics*. Chicago: University of Chicago Press.
- Durkheim, E. (1957). Professional Ethics, In *Professional Ethics and Civic Morals*. London: Routledge.
- Durkheim, E. (1973). The Dualism of Human Nature and Its Social Conditions. In *On Morality and Society*. London: University of Chicago Press.
- Durkheim, E. (1979a). Introduction to Ethics. In *Essays on Morals and Education*. Ed. W.S.F. Pickering. London: Routledge.
- Durkheim, E. (1979b). Review Lévy-Bruhl, La Morale et la Science des Moeurs. In *Essays on Morals and Education*. Ed. W.S.F. Pickering. London: Routledge.
- Edel, M. & Edel, A. (1959). *Anthropology and Ethics*. Springfield: CC Thomas Publisher.
- Ferguson, J. (1988). Cultural Exchange: New Developments in the Anthropology of Commodities. *Cultural Anthropology* 3: 488–513.
- Fesmire, S. (2003). *John Dewey and Moral Imagination: Pragmatism in Ethics*. Bloomington: Indiana University Press.

- Fortun, M. (2001). Mediated Speculations in the Genomics Futures Markets. *New Genetics and Society* 20: 139–156.
- Foucault, M. (1986). *The Care of the Self*, Random House edn. London: Penguin Books.
- Foucault, M. (1992). *The Use of Pleasure*. London: Penguin Books.
- Foucault, M. (1994). *The Order of Things: An Archaeology of Human Sciences*. New York: Vintage Books.
- Foucault, M. (1997). On the Genealogy of Ethics: An overview of Work in Progress. In *Ethics. Essential Works of Foucault 1954–1984*. Ed.1 P. Rabinow.1 London: Penguin.
- Fox, R.C. & Swazey, J.P. (1984). Medical Morality is Not Bioethics – Medical Ethics in China and the United States. *Perspectives in Biology and Medicine* 27: 336–360.
- Franklin, S. (2003). Ethical Biocapital. New Strategies of Cell Culture. In *Remaking Life and Death. Toward and Anthropology of the Biosciences*. Eds. S. Franklin and M. Lock. Santa Fe: School of American Research Press/James Currey.
- Frow, J. (1997). Gift and Commodity. In *Time and Commodity Culture. Essays in Cultural Theory and Postmodernity*. Oxford: Clarendon Press.
- Gabe, J., Calnan, M. & Bury, M. (1991). Introduction. In *The Sociology of the Health Service*. Eds. J. Gabe, M. Calnan and M. Bury. London: Routledge.
- Gammeltoft, T. (2001). Between “Science” and “Superstition”: Moral Perceptions of Induced Abortion Among Young Adults in Vietnam. *Culture, Medicine and Psychiatry* 26: 313–338.
- Geertz, C. (1973). Person, Time, and Conduct in Bali. In *The Interpretation of Cultures*, 2000 edn. New York: Basic Books.
- Geertz, C. (2000). *Available Light. Anthropological Reflections on Philosophical Topics*. Princeton: Princeton University Press.
- Gjerris, M. (2003). Bioetik og Pluralisme [Bioethics and Pluralism]. In *Der Må Da Være en Grænse! Om Holdninger til Ny Teknologi [There’s Got to Be a Limit! On Attitudes to New Technology]*. Ed. K. Lippert-Rasmussen. Copenhagen: Museum Tusulanums Forlag.
- Gorden, D. & Paci, E. (1997). Disclosure Practices and Cultural Narratives: Understanding Concealment and Silence around Cancer in Tuscany, Italy. *Social Science and Medicine* 44: 1433–1452.
- Graeber, D. (2001). *Toward an Anthropological Theory of Value: The False Coin of Our Own Dreams*. New York: Palgrave.
- Haimes, E. (2002). What can the Social Sciences Contribute to the Study of Ethics? Theoretical, Empirical and Substantive Considerations. *Bioethics* 16: 89–113.
- Harrison, F.V. (1991). Anthropology as an Agent of Transformation: Introductory Comments and Queries. In *Decolonizing Anthropology. Moving Toward and Anthrology for Liberation*. Ed. F.V. Harrison. Arlington, Virginia: Association of Black Anthropologists, American Anthropological Association.
- Hastrup, K. (2002). Menneskerettens Udfordring: En introduktion [The Challenge of Human Rights: An Introduction]. In *Menneskerettens Udfordring–Ideologi eller Videnskab? [The Challenge of Human Rights–Ideology or Wissenschaft?]*. Ed. K. Hastrup. Copenhagen: Akademisk Forlag.
- Hedgcoe, A.M. (2004). Critical Bioethics: Beyond the Social Science Critique of Applied Ethics. *Bioethics* 18: 120–143.
- Hoeyer, K. (2002). Conflicting Notions of Personhood in Genetic Research. *Anthropology Today* 18: 9–13.

- Hoeyer, K. (2003). "Science is Really Needed—That's All I Know" Informed Consent and the Non-Verbal Practices of Collecting Blood for Genetic Research in Sweden. *New Genetics and Society* 22: 229–244.
- Hoeyer, K. (2004). Ambiguous Gifts. Public Anxiety, Informed Consent and Commercial Genetic Biobank Research. In *Genetic Databases: Socio-ethical Issues in the Collection and Use of DNA*. Ed. R. O. Tutton Corrigan. London: Routledge.
- Hoeyer, K. (2005). The Role of Ethics in Commercial Genetic Research: Notes on the Notion of Commodification. *Medical Anthropology* 24: 45–70.
- Hoeyer, K., Olofsson, B.-O., Mörndal, T. & Lynöe, N. (2004). Informed Consent and Biobanks: A Population-Based Study of Attitudes Towards Tissue Donation for Genetic Research. *Scandinavian Journal of Public Health* 32: 224–229.
- Hoffmaster, B. (1992). Can Ethnography save the Life of Medical Ethics?. *Social Science and Medicine* 35: 1421–1431.
- Hoffmaster, B. (1994). The Forms and Limits of Medical Ethics. *Social Science and Medicine* 39: 1155–1164.
- Hoffmaster, B. (2001). *Bioethics in Social Context*. Philadelphia: Temple University Press.
- Holm, S. (1996). *Ethical Problems in Clinical Practice – A Study of the Ethical Reasoning of Health Care Professionals*, Ph.D., Department of Medical Philosophy and Clinical Theory, University of Copenhagen.
- Howell, S. (1997). Introduction. In *The Ethnography of Moralities*. Ed. S. Howell. London: Routledge.
- Jackson, M. (1982a). *Allegories of the Wilderness. Ethics and Ambiguity in Kuranko Narratives*. Bloomington: Indiana University Press.
- Jackson, M. (1982b). Meaning and Moral Imagery in Kuranko Myth. *Research in African Literatures* 13: 153–180.
- Jackson, M. (1998). *Minima Ethnographica. Intersubjectivity and the Anthropological Project*. Chicago: University of Chicago Press.
- Jackson, M. (2002). Familiar and Foreign Bodies: A Phenomenological Exploration of the Human-Technology Interface. *Journal of the Royal Anthropological Society* 8: 333–346.
- Joralemon, D. (2000). The ethics of the organ market: Lloyd R Cohen and the Free Marketers. In *Biotechnology and Culture, Bodies, Anxieties, Ethics*. Ed. P.E. Brodwin. Bloomington: Indiana University Press.
- Kaufert, J.M. & O'Neil, J.D. (1991). Biomedical Rituals and Informed Consent: Native Canadians and the Negotiation of Clinical Trust. In *Social Science Perspectives on Medical Ethics*. Ed. G. Weisz. Philadelphia: University of Pennsylvania Press.
- Kaufman, S.R. (1997). Construction and Practice of Medical Responsibility: Dilemmas and Narratives from Geriatrics. *Culture, Medicine and Psychiatry* 21: 1–26.
- Kaufman, S.R. (2001). Clinical Narratives and Ethical Dilemmas in Geriatrics. In *Bioethics in Social Context*. Ed. B. Hoffmaster. Philadelphia: Temple University Press.
- Kelly, S. (2003). Public Bioethics and Publics: Consensus, Boundaries, and Participation in Biomedical Science Policy. *Science, Technology and Human Values* 28: 339–364.
- Kleinman, A. (1995). *Writing at the Margin. Discourse Between Anthropology and Medicine*. Berkeley: University of California Press.
- Kleinman, A. (1999). Moral Experience and Ethical Reflection: Can Ethnography Reconcile Them? A Quandary for "The New Bioethics". *Dædalus* 128: 69–98.

- Knoppers, B. (1999). Status, Sale and Patenting of Human Genetic Material: An International Survey. *Nature Genetics* 22: 23–26.
- Kopytoff, I. (1986). The Cultural Biography of Things: Commoditization as Process. In *The Social Life of Things. Commodities in Cultural Perspective*. Ed. A. Appadurai. Cambridge: Cambridge University Press.
- Kroeber, A.L. (1952). *The Nature of Culture*. Chicago: University of Chicago Press.
- Laidlaw, J. (2002). For an Anthropology of Ethics and Freedom. *Journal of the Royal Anthropological Institute (MAN)* 8: 311–332.
- Lock, M. (2001). The Alienation of Body and Tissue and the Biopolitics of Immortalized Cell Lines. *Body and Society* 7: 63–91.
- Lock, M. (2002). *Twice Dead. Organ Transplants and the Reinvention of Death*. Berkeley: University of California Press.
- MacIntyre, A. (1984). *After Virtue*. (2nd ed.). Notre Dame: University of Notre Dame Press.
- Mauss, M. (1985). A Category of the Human Mind: The Notion of Person; The notion of Self. In *The Category of the Person. Anthropology, Philosophy, History*. Eds. M. Carrithers, S. Collins and S. Lukes. Cambridge: Cambridge University Press.
- Mauss, M. (2000). *The Gift. The Form and Reason for Exchange in Archaic Societies*. London: Routledge.
- McGee, G. (2003). Pragmatic Method and Bioethics. In *Pragmatic Bioethics*. Ed. G. McGee. Cambridge: The MIT Press.
- Muller, J. (1994). Anthropology, Bioethics, and Medicine: A Provocative Trilogy. *Medical Anthropology Quarterly* 8: 448–467.
- Nader, L. (1976). Professional Standards and What We Study. In *Ethics and Anthropology. Dilemmas in Fieldwork*. Eds. M.A. Rynkiewich and J.P. Spradley. New York: John Wiley and Sons.
- Nelson, J.L. (2000a). Moral Teachings from Unexpected Quarters: Lessons for Bioethics from the Social Sciences and Managed Care. *Hastings Center Report* 30: 12–17.
- Nelson, R.M. (2000b). The Ventilator/Baby as Cyborg: A Case Study in Technology and Medical Ethics. In *Biotechnology and Culture. Bodies, Anxieties, Ethics*. Ed. P. Brodwin. Bloomington: Indiana University Press.
- Nilsson, A. & Rose, J. (1999). Sweden Takes Steps to Protect Tissue Banks. *Science* 286: 894.
- Novas, C. & Rose, N. (2004). Biological Citizenship. In *Global Assemblages: Technology, Politics, and Ethics as Anthropological Problems*. Eds. A. Ong and S. Collier. London: Blackwell.
- Pálsson, G. (2002). Medical Databases. The Icelandic Case. In *Gene Technology and Economy*. Eds. S. Lundin and L. Åkesson. Lund: Nordic Academic Press.
- Pálsson, G. & Harðardóttir, K. (2002). For Whom the Cell Tolls. *Current Anthropology* 43: 271–301.
- Pálsson, G. & Rabinow, P. (2004). The Iceland Controversy: Reflections on the Trans-National Market of Civic Virtue. In *Global Assemblages. Technology, Politics, and Ethics as Anthropological Problems*. Eds. A. Ong and S. Collier. London: Blackwell.
- Rabinow, P. (1983). Humanism as Nihilism: The Bracketing of Truth and Seriousness in American Cultural Anthropology. In *Social Science as Moral Inquiry*. Ed. N. Haan. New York: Columbia University Press.
- Rabinow, P. (1999). *French DNA: Trouble in Purgatory*. Chicago: University of Chicago Press.

- Rabinow, P. (2003). *Anthropos Today. Reflections on Modern Equipment*. Princeton: Princeton University Press.
- Rapp, R. (2003). Cell Life and Death, Child Life and Death. Genomic Horizons, Genetic Diseases, Family Stories. In *Remaking Life and Death. Toward an Anthropology of the Biosciences*. Eds. S. Franklin and M. Lock. Santa Fe: School of American Research Press and James Currey.
- Rapport, N. (1997). The Morality of Locality. On the Absolutism of Landownership in an English Village. In *The Ethnography of Moralities*. Ed. S. Howell. London: Routledge.
- Read, K.E. (1955). Morality and the Concept of the Person among the Gahuku-Gama. *Oceania* 25: 233–282.
- Rose, N. (1999). *Powers of Freedom. Reframing Political Thought*. Cambridge: Cambridge University Press.
- Sahlins, M. (1972). *Stone Age Economics*. New York: Aldine Artherton.
- Sartre, J.P. (1977). *Existentialism and Humanism*. New York: M. S. G. Haskell House.
- Scheper-Hughes, N. (2000). The Global Traffic in Human Organs. *Current Anthropology* 41: 191–224.
- Scheper-Hughes, N. (2001). Commodity Fetishism in Organ Trafficking. *Body and Society* 7: 31–62.
- Scheper-Hughes, N. (2002). *Commodifying Bodies*. London: Sage.
- Scocozza, L. (1994). *Forskning for Livet. De Medicinske Forskningsetiks Forudsætninger og Praktikker – En Sociologisk Analyse [Research for Life. The Preconditions and Practices of Medical Research Ethics – A Sociological Analysis]*. Copenhagen: Akademisk Forlag.
- Scott, J. (1976). *The Moral Economy of the Peasant. Rebellion and Subsistence in Southeast Asia*. London: Yale University Press.
- Sharp, L.A. (2000). The Commodification of the Body and its Parts. *Annual Review of Anthropology* 29: 287–328.
- Shore, C. & Wright, S. (1997). Policy: A New Field of Anthropology. In *Anthropology of Policy. Critical Perspectives on Governance and Power*. Eds. C. Shore and S. Wright. London: Routledge.
- Shore, C. & Wright, S. (1999). Audit Culture and Anthropology: Neo-Liberalism in British Higher Education. *Journal of the Royal Anthropological Institute* 5: 557–575.
- Sigaud, L. (2002). The Vicissitudes of The Gift. *Social Anthropology* 10: 335–358.
- Spallone, P., Wilkie, T., Ettore, E., Haimes, E., Shakespeare, T. & Stacey, M. (2000). Putting Sociology on the Bioethics Map. In *For Sociology. Legacies and Prospects*. Ed. J. Eldridge. Durham: Sociology Press.
- Strathern, M. (2000). Introduction: New Accountabilities. In *Audit Cultures. Anthropological Studies in Accountability, Ethics and the Academy*. Ed. M. Strathern. London: Routledge.
- The International HapMap Consortium (2004). Integrating Ethics and Science in the International HapMap Project. *Nature Reviews Genetics* 5: 467–475.
- Titmuss, R. (1997). *The Gift Relationship. From Human Blood to Social Policy*. New York: The New Press.
- Tutton, R., Kaye, J. & Hoeyer, K. (2004). Governing UK Biobank: The Importance of Ensuring Public Trust. *Trends in Biotechnology* 22: 284–285.
- Waldby, C. (2000). *The Visible Human Project. Informatic Bodies and Posthuman Medicine*. London: Routledge.

- Walker, M.U. (1998). *Moral Understandings. A Feminist Study in Ethics*. London: Routledge.
- Weber, M. (1992). *The Protestant Ethic and the Spirit of Capitalism*. London: Routledge.
- Weiss, C.H. (1986). Research and Policy-making: A Limited Partnership. In *The Use and Abuse of Social Science*. Ed. F. Heller. London: Sage.
- Wexler, A.R. (2000). Chorea/graphing Chorea: The Dancing Body of Huntington's Disease. In *Biotechnology and Culture, bodies anxieties, ethics*. Ed. P.E. Brodwin. Bloomington: Indiana University Press.
- Whitt, L.A. (1999). Value-Bifurcation in Bioscience: The Rhetoric of Research Justification. *Perspectives on Science* 7: 413–446.
- Wolpe, P.R. & McGee, G. (2003). "Expert Bioethics" as Professional Discourse: The Case of Stem Cells. In *Pragmatic Bioethics*. Ed. G. McGee. Cambridge: The MIT Press.
- Zaner, R.M. (1993). *Troubled Voices: Stories of Ethics and Illness*. Cleveland: The Pilgrim Press.
- Zussman, R. (1992). *Intensive Care: Medical Ethics and the Medical Profession*. Chicago: The University of Chicago Press.
- Zussman, R. (2000). The Contribution of Sociology to Medical Ethics. *Hastings Center Report* 30: 7–11.