



ADVANCES IN MEDICAL SOCIOLOGY
VOLUME 9

**BIOETHICAL ISSUES,
SOCIOLOGICAL PERSPECTIVES**

BARBARA KATZ ROTHMAN
ELIZABETH MITCHELL ARMSTRONG
REBECCA TIGER

Editors

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BIOETHICAL ISSUES, SOCIOLOGICAL PERSPECTIVES

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INTRODUCTORY PREFACE

I am a sociologist. It is the way I think, the way I work, and the methods and the theory and the imagination I bring to the world.

But when journalists call to get a 'quotable quote' on some reproductive issue, a surrogacy case or sextuplets, a divorce 'custody' battle over frozen embryos or a celebrity adoption, they want to identify me as a 'bioethicist'.

Now why is that? Partly it is because as sociologists we have not made ourselves darlings of the media. I organized a panel on working with the media at the American Sociological Association one year, and a journalist pointed out that her job was to make things as simple as possible. And then Behrooz Ghamari, a sociologist, said "And our job is to make things complicated." It is true: What sociologists do is complicate the obvious, cast a critical eye on taken-for-granted truths, question assumptions and leave no 'obvious' fact unturned. No wonder the media does not like us.

And perhaps that is why the medical folks are often none too fond of us either. In a culture that wants to deny power, we focus our eyes on power. In America, a country that actively denies class, claiming middle class identity for all, we do a class-based analysis. We look at an occupation that values, first and foremost, doing no harm and measuring the many harms that are done. We look at people who see themselves – and strive to be – helpers of ailing humanity, and often show a very different picture.

And now we are turning our eyes to the field of bioethics itself. It is particularly complicated: The bioethicists, like the medical sociologists, are standing outside of medical practice and research, and offering a critique and an analysis. The topics that were long the province of medical sociology as a subdiscipline have been increasingly taken over by bioethics: the doctor–patient relationship, the concept of the self in illness and the institutional constraints on clinical practice. Whether at that level, or at the more grounded level of 'issues', from care of the dying to creating embryos, the person at the bedside taking notes, *not* in a white coat, is increasingly more likely to be a bioethicist than a medical sociologist. And so, small wonder, we medical sociologists started looking at the bioethicists themselves, taking that occupation as a subject of study, and that discipline as a body of knowledge to be analyzed.

In this volume, the first under my editorship of the *Advances in Medical Sociology* series, Elizabeth Mitchell Armstrong, Rebecca Tiger and I are going beyond this new “Sociology of Bioethics,” to refocus the sociological lens on the framing and management of bioethical issues at the micro- and the macro level. We think that looking at bioethics with a sociological imagination is a key way to advance the field of medical sociology. *Bioethical Issues, Sociological Perspectives* looks at what gets counted as ‘bioethics’ and – equally or maybe even more important – what gets left out of a traditional bioethical analysis that a medical sociological perspective can highlight.

We have organized this volume into four broad areas, and offer detailed introductions and overviews to the articles themselves for each section. But in brief, we begin by “Placing Bioethics Historically.” This is a new discipline, which has achieved national and international prominence with startling speed. A particularly American version of bioethics is being distributed around the world, and echoes of that show up throughout this volume.

The second section is perhaps the most traditionally ‘sociological’, as we offer a series of articles that look at “The Sociology of Working Bioethics: Private Narratives.” Just how does bioethics as a discipline and as a practice *work*?

In hospital committees, in the thinking of bedside practitioners, and in clinical settings, bioethics is ‘done’. The articles in this section go a long way towards showing just how, and what that has come to mean.

The third section discusses “Macrosociological Perspectives: Bioethics in the Policy Arena.” The new bioethics does not show up only at the bedside. Bioethicists and their way of thinking have entered into public policy. As Rebecca Tiger points out in her introduction to this section, issues picked up as ‘ethical’ have most often focused on individuals and individual decision making. But increasingly, discussions of bioethics inform public policy, and shape public discourse. Bioethics does so by framing issues, by highlighting some things and, as all disciplines do, by turning our eyes and our talk away from others.

The final section of the book makes a start at “Re-imagining Bioethics: Expanding the Borders of Bioethical Inquiry and Action.” Most especially, a sociological imagination looks at bioethics and asks questions beyond the level of the individual. It is true that anything can happen to anyone, as I point out when I teach introductory sociology to undergraduates. But there are patterns here; there are larger forces than individuals. Right and wrong, ‘ethical questions’, are not just individual choices and decisions. The choices

available to us, the questions that we ask, are embedded in a political economy. When we sociologists do bioethics, we do not start with the standard bioethical opening, hypothetical cases in which Patient Problem walks into Dr. Goodguy's office and presents an 'ethical dilemma'. For sociologists, there is a context, and that is how we complicate the question.

Running all through these sections are a variety of themes. Clearly, the relationship between the social and the individual is everywhere, in every article in which a sociologist looks at bioethics. Many of these also engage the issue of 'risk', a defining concept of our time. Risk society frames questions of medical practice in particular ways, as many of these articles show, from genetic counseling sessions to the use of circumcision to reduce HIV rates. Interrelated with questions of risk are questions of knowledge: These papers raise fundamental questions about knowledge itself: What constitutes medical knowledge and who is authorized to (re)produce and use it? And that, of course, segues into issues of imperialism more generally: not just occupational imperialism, but that of the nation-state. Several of these articles specifically address the uses of bioethical inquiry and framing on the export of American and European practices to under-resourced countries, and to under-resourced areas within America. Issues of justice inform a sociological perspective, asking us to see the environment(s) in which illness and medicine practices arise.

We also offer these articles as a testimony to sociological method. As sociologists, we bring to bioethics and its areas of study not only our critical voice, but also a methodological stance. Bioethicists themselves have been drawing on ethnography, and sociologists have been producing more and more ethnography of bioethical settings and practice.

This is what sociology brings to bioethics. But bioethics brings much to sociology as well. The use of narrative is an under-used technique of much value in sociology. It is no accident that much of 'autoethnography' focuses on patient narratives. Narrative has been of special interest in medical ethics and medical sociology because the illness experience is inevitably multi-layered, rich and complex. There are much data there to be constructed into a narrative. It is possible too that the inevitable helplessness one feels – as patient or as practitioner – in so much of medical work makes narrative particularly appealing and useful. To narrate is to make sense of, to order, by controlling the telling of events and experiences. By encouraging us to focus on narrative, bioethics advances our work as sociologists.

Beyond this methodological contribution, bioethics as a discipline has brought us back to some of the early work that was central in the development of medical sociology as a field. We can learn from reading the

work that bioethicists are doing, as well as from observing them in practice, the value of the rich ethnographies of hospitals and medical settings that were once so central to medical sociology. Health-care institutions are important sites for sociological inquiry, teaching us lessons that go beyond 'medical' sociology.

Amazing things are happening in the world of medical practice: Every day brings more news on 'breakthroughs' and treatment options, new technologies, drugs, practices and therapies. And many of them come with questions – journalists and the rest of society call on sociologists as well as bioethicists to raise those questions for the rest of us. Bioethics provides us an impetus to rediscover and to refresh our vision as sociologists, to exercise our sociological imagination on the issues that have captured the imagination of the world.

Barbara Katz Rothman
Editor

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CONTENTS

LIST OF CONTRIBUTORS	<i>ix</i>
INTRODUCTORY PREFACE <i>Barbara Katz Rothman</i>	<i>xi</i>
PART I: PLACING BIOETHICS HISTORICALLY <i>Elizabeth Mitchell Armstrong</i>	<i>1</i>
WHOSE BODY (OF OPINION) IS IT ANYWAY? HISTORICIZING TISSUE OWNERSHIP AND EXAMINING 'PUBLIC OPINION' IN BIOETHICS <i>Duncan Wilson</i>	<i>9</i>
FROM <i>CRUZAN</i> TO <i>SCHIAVO</i> : HOW BIOETHICS ENTERED THE "CULTURE WARS" <i>Renee R. Anspach and Sydney A. Halpern</i>	<i>33</i>
THE CHANGING CONTEXT OF NEONATAL DECISION MAKING: ARE THE CONSUMERIST AND DISABILITY RIGHTS MOVEMENTS HAVING AN EFFECT? <i>Rosalyn Benjamin Darling</i>	<i>65</i>
PART II: THE SOCIOLOGY OF A WORKING BIOETHICS: PRIVATE NARRATIVES <i>Barbara Katz Rothman</i>	<i>85</i>
"WHAT ARE WE REALLY DOING HERE?" JOURNEYS INTO HOSPITAL ETHICS COMMITTEES IN GERMANY: NURSES' PARTICIPATION AND THE(IR) MARGINALIZATION OF CARE <i>Helen Kohlen</i>	<i>91</i>

HEALTHCARE ETHICS COMMITTEES WITHOUT FUNCTION? LOCATIONS AND FORMS OF ETHICAL SPEECH IN A 'SOCIETY OF PRESENTS'	129
<i>Armin Nassehi, Irmhild Saake and Katharina Mayr</i>	
ETHICAL MINDFULNESS: NARRATIVE ANALYSIS AND EVERYDAY ETHICS IN HEALTH CARE	157
<i>Marilys Guillemin and Lynn Gillam</i>	
MAKING THE AUTONOMOUS CLIENT: HOW GENETIC COUNSELORS CONSTRUCT AUTONOMOUS SUBJECTS	179
<i>Daniel R. Morrison</i>	
PART III: MACROSOCIOLOGICAL PERSPECTIVES: BIOETHICS IN THE POLICY ARENA	
<i>Rebecca Tiger</i>	199
"...BUT YOU CANNOT INFLUENCE THE DIRECTION OF YOUR THINKING": GUIDING SELF-GOVERNMENT IN BIOETHICS POLICY DISCOURSE	205
<i>Svea Luise Herrmann and Sabine Könninger</i>	
CUTTING RISK: THE ETHICS OF MALE CIRCUMCISION, HIV PREVENTION, AND WELLNESS	225
<i>Ananya Mukherjee</i>	
GENOMICS, GENDER AND GENETIC CAPITAL: THE NEED FOR AN EMBODIED ETHICS OF REPRODUCTION	245
<i>Elizabeth Ettorre</i>	

**PART IV: RE-IMAGINING BIOETHICS: EXPANDING
THE BORDERS OF BIOETHICAL INQUIRY AND
ACTION**

Elizabeth Mitchell Armstrong 263

**WHAT DOES JUSTICE HAVE TO DO WITH IT? A
BIOETHICAL AND SOCIOLOGICAL PERSPECTIVE
ON THE DIABETES EPIDEMIC**

Claudia Chaufan 269

**SOCIOLOGICAL CONTRIBUTIONS TO DEVELOPING
ETHICAL STANDARDS FOR MEDICAL RESEARCH
IN VERY POOR COUNTRIES: THE EXAMPLE OF
NEPAL**

Mark Tausig, Janardan Subedi and Sree Subedi 301

**CHANGING THE SUBJECT: SCIENCE,
SUBJECTIVITY, AND THE STRUCTURING
OF ETHICAL IMPLICATIONS**

Sara Shostak and Erin Rehel 323

PART I: PLACING BIOETHICS HISTORICALLY

Like all tribes, bioethics has its own origin myths. According to these myths, bioethics emerged in the latter half of the twentieth century when new technologies and scientific developments challenged the norms that had traditionally governed clinical practice. Theologians, philosophers, clergy, judges, lawyers, journalists and ordinary people – the “strangers at the bedside” in David J. Rothman’s memorable phrasing – began to take an interest in moral matters that previously had been the realm of physicians alone. Codes of research ethics were formulated in response to the Nazi atrocities; hospital ethics committees were established in sensitivity to the emerging notion of “patients’ rights.” Bioethics was born.

The three papers by Renée Anspach and Sydney Halpern, Duncan Wilson, and Rosalyn Benjamin Darling in this first section show us in fine-grained detail who these strangers at the bedside were and how they have and have not changed the practice of medicine and biomedical research; they show us the multiple and sometimes contradictory origin points of the enterprise that today we recognize under the rubric “bioethics.” Each paper takes the long view of a particular enduring issue in bioethics: the right to die, human tissue research, and decision making in the neonatal intensive care unit (NICU). Precisely because these papers focus on matters that have preoccupied and vexed bioethicists from the very beginning, they constitute an important corrective both to a linear view of the progress of the field and to universalist notions of bioethics. Each paper shows us how time, place and context matter deeply, as well as how things have changed and how they have stayed the same. Moreover, they offer a revisionist perspective on certain key moments in the official history of bioethics. Together they show us “how history can help empirically ground moral concepts as historically and culturally contingent,” in the words of Duncan Wilson.

In the second paper, “From *Cruzan* to *Schiavo*: How bioethics entered the ‘culture wars’,” Renée Anspach and Sydney Halpern use the cases of Nancy

Cruzan and Terri Schiavo as a kind of “natural experiment,” as they put it. The year that Cruzan’s saga ended with the court-sanctioned removal of her feeding tube – 1990 – was the beginning point of the Schiavo story, with her unexplained collapse at home and subsequent lapse into a mental state that was variously diagnosed as a persistent vegetative state, “a minimally conscious state,” and, most famously, “not somebody in a persistent vegetative state” by Senate majority leader Bill Frist on the Senate floor in March 2005. While both women became the focal point of national attention and crystallized widespread discussion of end-of-life issues among the general public, the Cruzan and Schiavo cases were in fact framed very differently both by the mass media and by the experts who claimed to speak as bioethicists in each case.

By examining the coverage of the two cases in a single newspaper, Anspach and Halpern are able to show that despite the parallel facts in each case, the two stories were depicted very differently in the mass media. The Cruzan case was at the time and is still today seen as a “right to die” case; indeed, the United States Supreme Court ruling is often regarded as a definitive legal moment in the history of the right-to-die movement in the United States. The Schiavo case, however, was portrayed as a “right to life” case, with Terri Schiavo’s parents fighting to keep their daughter alive while her husband Michael Schiavo sought to have her feeding tube removed. Anspach and Halpern, in fact, use these disparate core frames to argue that “the discursive ground had shifted.” Most notably, religious conservatives had begun to organize and present themselves as Christian bioethicists, thus implying that bioethics as a field had begun to crystallize into distinct subgroups. Right-to-life advocates – mainly abortion opponents – had been involved in the Cruzan case, mounting a series of small-scale and last-minute protests and vigils outside the Missouri Rehabilitation Center, as well as filing a series of court challenges, all of which were turned down. In contrast, right-to-life advocates acted as an organized, coordinated and influential mass movement in the Schiavo case, ultimately bringing their battle to the Florida governor’s office (occupied at the time by Jeb Bush, brother of the President), the Florida legislature, the U.S. Congress, the White House, and the Vatican, all of which denounced the removal of Schiavo’s feeding tube as an act akin to murder. These are some very prominent and politically powerful strangers indeed.

Anspach and Halpern note that while the medical facts in the Cruzan and Schiavo cases were virtually identical – both women were in a persistent vegetative state, without higher brain function, able to breathe unaided, but unable to swallow or eat and thus dependent on a feeding tube, with no