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## **From Square Problems to Round Reasoning:**

### **A Systems Theoretical View of Medical Ethics Problems and Their Solution Practices**

#### **The Advancement of Medicine and the Resulting Problems: an Introduction**

Cardiologists and public health experts in Finland recently debated the start threshold of cholesterol medication. Cardiovascular medical specialists would like to stretch the newest care practices based on the latest research results as far as possible in order to prevent cardiovascular disease, for which the Finnish population has a relatively high risk. Public health specialists, for their part, warn about medicalization and point to rising figures in medical care costs in general. Which of these experts, trained in the same medical schools, should we believe and rely on?

Advancements in the field of transplantation surgery, for example, have led to a situation in which a clear demarcation between life and death is blurred. When should a human being be declared dead? When the brain ceases to operate? When the heart stops pumping blood? Or when there is irreversible lung failure? Which of these would be a (medically) comprehensively reasoned answer?

A child born in the 22 week of pregnancy can be saved, thanks to practices based on current advanced and highly differentiated medical science. At the same time a medically safe termination of a pregnancy can be made up to the 24 week if serious impairment is found in the fetus through amniocentesis or ultrasound scan. Moreover, the heart of fetus starts to beat, on average, in the twelfth week. In view of the above-mentioned cases, the question arises of how to make rational demarcations based on the very principles of medical science that are blurring the issues.

As by-products of the current level of efficiency in medical diagnostics, care and prevention practices, which are based mainly on advancements in modern bioscience, a large number of problems and their

repercussions is constantly being generated. A distinguishing characteristic of these problems is their insolubility in the sphere of their origins alone. Moreover, they tend to reach across the lines of medical science and clinical practice and demand comprehensive and continuous consideration. Questions of the start threshold of cholesterol medication, the demarcation between life and death, and the manifold issues related to the moment of safe or acceptable abortion resonate through all of society. All of these *problématiques* and the solutions proposed for dealing with them have clear juridical, economic and political implications as well as religious and ethical implications. This polycentrality illustrates the current thickening of communication through all of society and demands a social-theoretical scrutiny.

Various types of medicine-originating problem clusters that are wide-ranging in their consequences, from difficulties in the formulations of problem-based care recommendations to anxiety in individual world views, are often labelled 'ethical problems'. To consider these issues, growing numbers of problem-based organizations, ethics committees and commissions as well as advisory boards of all kinds have been set up. Along with various medical experts, these organizations often boast ethics specialists trained on philosophy or theology faculties. In addition there are usually people from areas affected by the problems in question and their solutions, such as economics and law specialists, members of parliament as well as laymen and representatives of patient organizations.

A sociologically significant characteristic in the working of these committees, commissions and discussion groups is the lack of dominance of either ethics or medicine. Even though the problems are often labelled ethical, trained ethical specialists seem to be only one party among others in the working meetings. Instead, the 'ethics' can be found largely in the problem-solving procedures. The work of ethics agencies seems to be ethical—or even 'ethicizing'—in a practical sense, namely ethical ways of considering the issues and treating the participants 'ethically', that is to say, equitably.

This empirically-found ethics is at the centre of the present text. In this regard various practices for dealing with the wide-ranging *problématiques* and the repercussions stemming from the sphere of medical research and clinical practice come up for scrutiny. The background for my interest in current medicine-related empirical ethics is the rise of different types of ethics committees since the 1960s. Moreover, the potential link, firstly, between the emergence of various ethical problems and their tendency to become outsourced from the medical profession itself and, secondly, the rise of so-called evidence-based medicine (EBM) along which care practices are firmly rooted in current medical research has been a central source of inspiration for my study. Why is the number of problems labelled 'ethical' rising at the same time as the readiness and capabilities of medical specialists to solve these problems is apparently declining? Ultimately, what is the role of academic ethics in the practices of organizations, such as health care ethics committees, whose participants mostly lack ethics education in the academic sense? And what is the concrete 'ethics' of such committees and advisory boards?

My examination of these questions proceeds from the tradition of sociological systems theory. I argue that the emergence of these committees, as well as the concrete actions taken by them cannot be fully understood by limiting the inquiry to the phenomenon itself. Instead, the underlying idea of my systems theoretical examination is to illuminate the 'ethical' practices taking place in committee and board meetings by situating the phenomenon in its wider societal context and vice versa, namely examining the wider context as a means of understanding the phenomenon being studied.

In the tradition of the Luhmannian systems theory this means keeping an eye on the continuous chaining and un-chaining, thickening and un-thickening of communication via certain historically moulded logics, which seem to have branched off from each other over the centuries. Economics, law, politics and science, for example, are constituted differently through distinct criteria, both historically and currently, owing to constantly changing practice. These evolving logics of communication chaining can appear simultaneously in the same concrete locations, especially in the contexts of organizations. In

this regard the basic challenges in the work of ethics committees become clearer when examined through a systems theoretical lens.

The basic challenge of current health care ethics committees is thus obvious: Committee participants come from and represent different areas of society, yet the ideal of committee work is based on a symmetrical round-table discussion rather than on segmentation and the dominant expertise of certain fields, discourses and rationales. The central question inspired by the systems theoretical point of view is as follows: How does the round-table model work in practice? Moreover, what kinds of arrangements are required to balance the various logics brought by the members of organizations from different fields? The exact role of 'ethics' is of utmost interest here as well. If committee and advisory board meetings are to be held on a round-table basis, then academic ethics cannot be the dominating discourse. The ethics in the context of the committee meetings, which emerges in such meetings, thus presumably differs from mere academic ethical reasoning.

In this essay I consider these questions by moving from the highly general and theoretical to the more particular and empirical. In the following section the focus is on modern medicine, understood both as biomedical research and clinical practice. The constitutive characteristics and foundations of these fields are investigated here along with modern hospital organization as the concrete location where 'medicine happens'. The reference point for these observations stays in medical ethics, however. The current role of coupling medical practice strictly with science within the paradigm of evidence-based medicine becomes significant when the roots of the 'outsourcing of the a-medical' are traced. In the third and final section, the role of medical science and medical care as 'producers' as well as 'outsourcers' of assorted 'ethical' problems, which are riding on the coattails of the huge advancements in these fields, is combined with the systems theoretical view of a polycontextual society and empirical ethics as ethicization rather than ethical reasoning. This is done in the context of one Finnish health care advisory board<sup>1</sup>. In this final section, the examination alternates between an empirical observation of the concrete work of an ethics committee and a systems theoretical theory of society, thus providing an opportunity to analyze the operations of ethics committees in a wider societal context.

## **The Self-Demarcation of the Medical Sphere and Ethical Problématiques: Locations and Influences**

The field of health care in its various forms is no doubt one of the most remarkable and influential in contemporary society: Health-related communication resonates throughout society, and health-related issues are broadly and deeply connected with many central organizations and their decision-making processes. When health care is observed by means of systems theory, a central question still concerns the role of medicine as a potential system: Are systems characteristics found in the field sphere of medicine? Is it possible to locate an *Eigenlogik* in health care practices, with which it would be possible to construct a system of health care or medicine? Luhmann's own observations (1983a, b, as well as 1990) on this 'odd system' have been exiguous, but lately the discussion seems to be heating up (see Bauch 2000; Vogd 2005; Hafen 2007; Stollberg 2009; Pelikan 2007a, b as well as 2009; also Saake and Vogd 2008). Even so, there is no consensus on a systemic character of the field of medical care.

Even though my analysis draws on the theoretical train of thought of Luhmannian systems theory, the general question of the systems characteristics of medicine is not at the core of my argument. Instead of offering a general illustration and remaking the previous and mostly laudable deliberations on

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<sup>1</sup> My own empirical research (started in 2009) concentrates on a national Finnish ethics board, the National Advisory Board on Social Welfare and Healthcare, ETENE ([www.etene.fi/en](http://www.etene.fi/en)). The empirical interpretations are preliminary at this point.

systems of delivering medical care, I will focus on *the elements underlying the emergence of ethical reflection and the need for such reflection in current medicine, especially on the profession's borders*. In my argumentation, issues which do not resonate with the current, research-based logic of medicine are bound to get outsourced. In this regard, I speak of *a-medical* issues in contrast to medical and non-medical ones, referring to questions to which current medical rationale is rather indifferent.

### ***Outsourcing the A-Medical? Evidence-Based Medicine and Self-Demarcation***

At this stage my working hypothesis is as follows: In recent decades there has been a shift in the (scientific) rationale underlying medical practice. This shift, gradual rather than swift, can be formulated in various ways depending on one's point of view and emphasis: from particular treatment to universal medical knowledge; from craftsmanship to formulas; from individual and precise diagnostics to curative and preventive therapy, for example. A common denominator among these is the umbrella label of evidence-based medicine (EBM), a new approach—or even, since the early 1990s, a new paradigm—both in research and clinical work, as well as in teaching medicine.

A new paradigm for medical practice is emerging. Evidence-based medicine deemphasizes intuition, unsystematic clinical experience, and pathophysiological rationale as sufficient grounds for clinical decision making and stresses the examination of evidence from clinical research. (Evidence-Based Medicine Working Group 1992, p. 2420)<sup>2</sup>

These are the opening lines of the text that initiated the EBM-era in Anglo-American medicine, written by a group of eminent medical specialists and published in the high-ranking *Journal of the American Medical Association (JAMA)* in 1992. The article was quickly followed by a burst of publications, ranging from the influential series of *The User's Guides to the Medical Literature*, also published in *JAMA*, to various articles, textbooks and lay publications. The new and growing paradigm quickly and effectively achieved status as the true paradigm in medical science across the English-speaking medical community.<sup>3</sup>

Even though all of the new features of EBM, which have since caught on, mentioned in the opening paragraph of the original *JAMA* article are important advances in recent medical research and clinical practice, a wider perspective is needed in order to analyze and summarize the new and deeper tenets of the EBM paradigm. The assumed change in rationale is formulated most precisely in *epistemological* terms: Pathology is no longer king; rather, epidemiology and population health reign. As two American sociologists of health and illness, Stefan Timmermans and Emily S. Kolker (2004, p. 183), aptly put it:

More than standardized format of clinical practice guidelines, in terms of professional knowledge the key finding is that these guidelines constitute a shift in the medical knowledge base from pathophysiology to epidemiology. The randomized clinical trials have replaced the autopsy as the gold standard in medicine, and it has consolidated a quantitative, population-based way of looking at health and illness.

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<sup>2</sup> The term evidence-based medicine first appeared in the published literature the previous year, in 1991. It was evidently this particular *JAMA* publication that brought both the term and the general idea of EBM to a wider medical public and started the triumphal march of the new paradigm (Montori and Guyatt 2008; see also Liberati and Vineis 2004 for a more critical summary). It is also possible to trace the roots of EBM back to Archie Cochrane's lectures in epidemiology and research methods from 1972 (see Ashcroft 2004, S. 131).

<sup>3</sup> In Finland EBM orientation began to take root shortly after the original *JAMA* article and the first official EBM guidelines were published in Finnish in 1997 by the Finnish Medical Society *Duodecim*.

My own argument relates to the *transition from a realist-orientated epistemology to one of statistical empiricism*. There has been a shift from *realism*, first tracking the symptoms of real (individual) pathological bodily mechanisms and then curing them, to strict *empiricism* in the form of (population) statistical correlations and probabilities of the *efficacy* of one medical method—be it curative or preventative—in relation to other potential methods. In other words, the knowledge base of medicine, or in systems theoretical parlance, the means of reducing the contingency intrinsic to medicine, whether in the form of research or clinical practice, has been changing in recent decades, and this has to be put into a wider societal context.

The much needed, research-based evidence of the efficacies of different treatment methods plays a central role here. In a solid argument based on the model of the Insufficient Non-redundant component of Unnecessary Sufficient complex (INUS) introduced by the philosopher John Mackie (1974), Paolo Vineis (2004, p. 127), a professor of environmental epidemiology, highlights the role of evidence in clinical decision making as a necessary, non-redundant component and states: ‘without evidence there will never be good clinical decisions’. Moreover, to base clinical decisions on evidence also has a strong *ethical emphasis*: Causing patients unnecessary harm can be avoided, and health care in general can be improved. No money is wasted on ineffective treatment. This deeply ethical core of EBM is repeated often in texts considering the main goals of medicine and was recently summarized by a professor of pediatrics, Mariana Kruger (2010, p. 69):

Evidence-based medicine enables the health care practitioner to strive for a clinical ideal, which addresses our ethical responsibility towards the best interest of our patient. For this purpose health care professionals should pursue health. This should be done through the pursuit of the most effective ways of achieving health, which is a generally acceptable value shared by most people. As professionals it is through the pursuit of truth, that we will find most effective means to health.

The need for evidence converges in daily clinical practice with the principle of necessity for the physician, as a decision maker, to ‘trade the benefits and risks, inconvenience, and costs associated with alternative management strategies, and in doing so consider patient’s values’ (Evidence-Based Medicine Working Group 2002, p. 5). But to absorb these rather vague categories of values and preferences, an ever-growing number of EBM-tools is at the physician’s disposal in clinical encounters with patients. As the authors of *The User’s Guides to the Medical Literature* continue: ‘The explicit enumeration and balancing benefits and risks that is central to EBM brings the underlying value judgments involved in making management decisions into bold relief’ (ibid., p. 6). Who wants to make (unethical) clinical decisions based on weak or no scientific evidence?

The crucial point in current medicine is thus the move from ‘evidence to action’. The clinical practice (‘the action’) has to be solidly based on evidence, no question. But only based on evidence, not reduced to it—and by this, uncertainty and contingency tend to remain persistent bothers for medical care, despite all the formal tools and instruments developed to hide them. Also the intensification of medical treatment today is made possible by concealing and restraining various forms of inescapable contingencies intrinsic to medical work. Observed empirically, the habitual fixity and time limitations of diagnosis and therapy practices, for example, play a central role in this regard by securing the constant chaining of medical communication (to medical communication) and thus holding back uncertainty and contingency.

The systems theoretical concepts of *the symbolically generalized communication medium* of a system, by which the (certain) chaining of communication is enabled in the first place and also made more probable during the continuous chaining of communication, provides an important insight here. If, for example, we consider all the possible forms of practice during which economic communication is constantly connected (to economic communication) without its nearly universal symbolically generalized

communication medium, money—whether in the form of a piece of metal, paper or the figures of ones and zeros –, the significance and role of a symbolically generalized medium as an important reducer of contingency becomes clear.

I am following Jürgen Pelikan's view (2007a, p. 89–91 and 2007b, p. 297–300), in which various care and treatment *standards and guidelines* based on biomedical and statistical research operate as *symbolically generalized communication media of medicine*. In the doctor-patient encounter this crucial medium consists of *confidence* in (scientific) knowledge on which the treatment practice is based and *trust* in the doctor as a competent master and utilizer of this special knowledge (cf. Stollberg 2009, p. 205–206). However, this view, namely that generalized media can be found in the medical sphere, should not be read as a statement for a distinct 'medicine system'. The systems-likeness of medicine is not among the most interesting questions here, considering the task at hand.

Instead, an observation of the role of the mediating logics provides fruitful possibilities for scrutinizing the characteristics of current medical care as well as sources of ethics-related problems and their reflection practices. As mentioned above, generalized media operate as (necessary) reducers of contingency in organizational practice, such as various treatment operations with deadlines (*sic*). A highly interesting question concerns the role and characteristics of a medium coupling two different logics, clinical medicine and medical research, of which the latter is solidly based on (mostly bio-statistical) science. In my argument various clinical guides, manuals and handbooks, especially clinical practice guidelines or current care guidelines, which, in the era of EBM, are also called evidence-based medicine guidelines (EBMG),<sup>4</sup> play a central role: The critical link, permeated with the contingency between medical research and clinical practice, is built continuously during daily clinical practice by using the EBM-based guidelines as tools for medical decision-making.

These guidelines, assembled mostly by internationally acknowledged medical experts in each specialty and based on the latest results of efficacy largely proven by randomized controlled trials (RCTs), make certain diagnoses, prognoses, treatment models and modes of prevention more probable than others in the constant and largely hectic practice of medical organizations. On the other hand, various guidelines also operate as effective distributors of responsibility, producing a wider, 'scientifically proved' background for everyday clinical practice. From the point of view of responsibility, evidence-based medicine thus produces a remarkable broadening of collegiality. Once again, who wants to make clinical decisions on less research-based and less collegial grounds?

But these instruments do not completely succeed. To understand why this is, their role in medical practice has to be contextualised. There is no escaping contingency in the field of medicine. Contingency can even be interpreted as a universal component of medicine in general and of clinical work in particular. The attempts to suppress this intrinsic character have varied through history, but the basic dilemma is hard to avoid: the application of general, standardized or otherwise compressed knowledge, whatever its source, to particular objects, contingent in their physiology and behaviours. As a group of influential medical experts put it, 'A continuing challenge for EBM—and for medicine in general—will be to better integrate the new science of clinical medicine with the time-honored craft of caring for the sick' (Evidence-Based Medicine Working Group 2002, p. 9). This fluidity cannot—and according to some medical experts, should not (e.g. Vineis 2004)—be dichotomized and thus instrumentalised away.

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<sup>4</sup> The Finnish EBMG-pages in English, based on the colossal international Cochrane-database (<http://www.thecochranelibrary.com>) can be found at the website <http://www.terveysportti.fi/pls/ebmg/ltk.koti> and include almost one thousand care guidelines, over 3,500 evidence summaries and over one thousand pictures, all of which can be downloaded onto mobile phones and hand-held computers, thus enabling physicians to use them during treatment.

The transition from pathophysiology to epidemiology and clinical epidemiology (see e.g. Sackett 2002) as a cornerstone of medical reasoning aided by EBM-statistics and guidelines does not truly change things, despite the hopes of advocates (e.g. Armstrong 2007; Jensen 2007; Timmermans and Mauck 2005; Timmermans and Kolker 2004; cf. Hacking 1975 and 1990). Moreover, the standardization movement reveals the heterogeneity of the whole field; there is actually a huge variation in the experiences of utilizing evidence-based knowledge in relation to specialties, as well as in the types of education and the years of service of physicians (Timmermans and Berg 2003, p. 142–165).

Besides, the rise of the EBM paradigm and the use of various guidelines can be interpreted as posing major challenges to the medical profession (see e.g. Timmermans and Mauck 2005; Haug 1988; Ritzer and Walczak 1988; Vogd 2002; Sulilatu 2008). One challenge stems from the view that, even though evidence-based medicine is effective in clinical practice, this ‘effectiveness’ can be evaluated by many different criteria. Some critics thus see EBM as a lightning rod bringing foreign logics to the field of medicine (e.g. Kristiansen and Mooney 2004). Rather than an effective means of improving medicine, evidence has also been used as ‘an ideology’, ‘as a justification for many agendas in health care, ranging from crude cost cutting to the promotion of extremely expensive technologies with minimal marginal returns’. (Evidence-Based Medicine Working Group 2002, p. 10–11). Above all, there is the logic of *economy*, as a general principle of organizational management connected with the rise of the monetary calculation of inputs and outcomes. These calculations can be characterized by an informative trisection of rationalization, rationing and prioritization (see e.g. Fuchs et al. 2009). In everyday medical practice these emerge in the form of (increased) budget steering and effectiveness calculation, with or without medical criteria and in various arrangements and classifications of patients and their conditions, such as diagnosis-related groups (DRGs; see e.g. Mayes 2007). Usually, this means one thing: time limits. Another strong contender as a guarantor of effective treatment is the logic of *law* with emphasis on individual freedom, rather than the paternalism intrinsic to medical care. This argument culminates in the debates over the rights of the patients, often today in the form of so-called informed consent.

Observed from this contextual point of view, the science connection seems to be a double-edged sword, whether medicine is observed as a system or a profession. The science-based means of contingency reduction is a lifeline for the frictionless chaining of medical practice in its hectic daily working environment. At the same time the maximum effort being made to eliminate contingency from medical practice—above all, with the principles of EBM—threatens the societal position of the medical profession and its autonomy. This presumably happens in two ways: by narrowing the doctor’s work to that of a cook using a cookbook written by biostatisticians and filled with too many detailed recipes that leave no room for improvisation; and by paving the way for foreign logics to intrude into the core of the profession. But one has to keep in mind that the roots of EBM lie deep within the medical profession: in epidemiology and its clinical variant, in Archie Cochrane’s lecture series in 1972 on the effectiveness and efficacy of health services, and finally, in the influential work of the Evidence-Based Medicine Working Group from the early 1990s on. Thus, if the EBM orientation really leads to the weakening of professional autonomy and medicine’s power, this is ‘to some extent from profession’s own doing or at least an unintended consequence of its dominance’ (Timmermans and Kolker 2004, p. 180).

In sum, western medical practice today is inseparable from bio-medical scientific research. The profound continuum of medical research and clinical practice together with medical education, which maintains and reproduces this connection, enables the practice of biomedicine in its current effective form. Intrinsic ambivalences unavoidably connected to diagnosis, treatment and prevention practice are currently concealed, largely through myriad clinical guidelines that provide the basis for connecting science and medical practice in the first place.

That being said, *the total elimination of contingency remains an illusion*. The connection of clinical practice with medical research via EBM-guidelines never fully succeeds. First of all, the objects of all medical work are themselves complex. The isolation of sick bodies from their psycho-social interrelations and, moreover, from the societal contexts from which they come and where (hopefully) they end up, is too burdensome to be achieved completely in medical practice, which is understood as covering all aspects of medical care from operating theatres to general practices (see e.g. Mol 2002 and 2008). Secondly, some remarkable epistemological and methodological problems can be traced back to the research that provides ‘the evidence’, such as the inconsistencies between theory and evidence in the first place (see Worrall 2010), as well as the problematic nature of and relations between evidence, clinical effectiveness and inference and the crucial point of elaborating on causal mechanisms from correlations (e.g. Ashcroft 2004; Vineis 2004).

Thirdly, EBM can be seen as a demarcation principle between true evidence-based scientific medicine and other types of curing practices or quackeries. Yet simultaneously, the emphasis on epidemiological and population health seems to widen the scope of ‘medical’ prevention: Physicians are encouraged to consider the overall well-being of patients. Broader issues of societal health and health policy thus cannot be dismissed from consideration by definition. If a strong and consistent association between socioeconomic status and health, for example, does exist, should physicians then consider how these factors could contribute to reducing poverty? Or should physicians be ‘concerned with the polluted air that patients are breathing? We believe they should’. (*User’s Guides* 2002, p. 9). In the era of EBM, if a strong correlation between x and health exists, then physicians cannot close their eyes to x, no matter how vague or how far from principles of traditional medical treatment and prevention x may be.

Is there more room for ethics in current medicine then? To put it broadly, the shift in the core of medical rationale and style of reasoning—from epistemologically realist, pathophysiological and diagnostics centred towards RCT-based empirical evidence as the *sine qua non* for medical treatment—leaves less room for consideration of scientifically-backed issues. Moreover, the logic of EBM offers an overall societal justification distinct from other ‘unscientific’ forms of treatment and provides strong support psychologically and in concrete—especially juridical—problem cases by widening collegiality. EBM’s strong science connection thus constitutes the medical profession’s self-understanding as having science-based clinical expertise capable of using the newest healing techniques, which are carefully RCT-tested for effectiveness. This understanding is manifested in the emphasis on an inseparable ‘ethical’ component of evidence-based medicine along with the demarcations from former, questionably paternalistic rationales (e.g. Kruger 2010; see also Ashcroft 2004).

From the point of view of theory of society, the most pertinent point in regard to ethics, understood as a reflection theory of morality, is the relation between ethics considerations and connections in current medical practice: Ethics does not resonate with the bio-statistical and epidemiological research agendas that are behind current medical practice, even though these agendas fundamentally follow current ethical standards. Nor does ethics resonate with logics foreign to medicine, especially those of economy or law. If clinical decisions are based on research evidence as much as possible, then ethics issues cannot play a central role in everyday clinical practice. This is not because of some general aversion to ethics in medicine, but rather because of the emphasis on efficacy in all medical practice in terms of being evidence-based. *No evidence, no use; a-medical issues are outsourced first*. The ethics of medicine is thus of a different kind from ethics problems and moral reasoning. It is likelier to be found deeply interwoven in the self-understanding of the medical profession: Medicine as the practice of healing is intrinsically ethical.



## ***Outsourcing the A-Medical? The Fundamental Ethics of Medical Practice and Ethical Issues in Science-Based Medicine***

'It is a physician's duty to protect human life and alleviate suffering. The main goal of her work should be the enhancement of health and its attainment' (Suomen Lääkäriitto 2005, p. 10)<sup>5</sup>. This duty-ethical principle of protecting life and relieving human suffering is a cornerstone of all medical practice. Because of the characteristics of its objects, human beings suffering from or being threatened by bodily pathologies, *medicine will never be without ethical content*. 'Ethicality' is, along with 'respect for life', 'humanity', 'high vocational proficiency' and 'collegiality', one of the five 'basic values of a doctor' (ibid., p. 13).

An ethical aspect can thus be seen as being intrinsic to all care-related practice and as an ever-present element in the physician's work. During the interaction between a doctor and a patient, there is a social dimension, the 'humane level', present as well, in addition to the merely professional, structural-dimensional 'doctoring'. This humane aspect is formulated in the above-cited Finnish handbook of physician's ethics as follows: A physician's goal is 'to perceive the inner world of a human being who is suffering and to consider her as a unique person. A physician is thus simultaneously a distant expert and a close, understanding human being', (Ibid., p. 17.)

However, this vocational ethicality of the physician's daily work and the intrinsic ethicality of all healing differs from the ethics problems and ethical reasoning involved in intractable moral issues. The key question relating to the rise of organizations which deal with problems perceived as 'ethical' concerns the actual 'ethicality', that is, the nature of the ethical component of medical problems: *What kinds of questions are labelled problematic in the ethical sense and relegated to the tables of ethics committees, and how do these ethical problématiques relate to—and stem from—recent advancements in medical care and research?*

Novel openings in new areas, both in medical research and in clinical practice, abound, and these call for reflections on ethics. In addition, the pace of different technologies—above all, in the fields of diagnostics and risk assessment—began to accelerate in the last decades of the twentieth century. The increase in the possibilities of utilizing advancements in biotechnology, most recently, in the field of molecular genetics, has been a crucial development from the viewpoint of recent ethics-related issues (cf. the 'geneticization' of society as early as Lippman 1991; see also ten Have 2001). For example, the problem related to the inescapably 'decisionistic' nature of issues in determining the actual limits of human life, made possible, above all, by the use of DNA analyses, has led to an increase in problems perceived as deeply ethical (see e.g. Jallinoja 2002a; also Meskus 2009, p. 138–150).

Two salient points relating to the kind of persistent *problématique* often perceived as ethical<sup>6</sup>, such as issues of defining human life and its boundaries, the termination of active treatment and the prioritization of care, can be highlighted. Firstly, the problems run deep and concern basic values and principles, not only in medicine, but also for humanity in general. A second and related point is that these issues resonate through all of society. Along with general, scholarly and theological reflections, these issues have a clear impact on such areas as law, economics, politics and education. Hence, the discussions and deliberations of the problems—both deep and wide in their nature and ramifications—reach across their fields of origin to current medical research and practice.

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<sup>5</sup> All translations from Finnish to English are the author's.

<sup>6</sup> The demarcations of ethical problems are flexible as a matter of course and the gamut of issues described as 'ethical' by doctors seems to be fairly wide (see DuVal et al. 2001 and 2004) and differs from the definitions of professional ethicists (see Self et al. 1993).

Some connection among ‘the scientification of medical care’, especially in the form of EBM, the production of persistent *problématiques* with broad, non-medical repercussions, their labelling as ‘ethics’, above all, by physicians themselves, and their outsourcing to problem-based organizations<sup>7</sup> operating mostly outside daily medical practice, be it medical research or clinical practice, seems rather likely. In the Finnish context<sup>8</sup> the medical profession took part in the ethics discussions from the outset of the rise in ethics agencies during the late 1990s (see Meskus 2009, S. 146). This does not, however, change the fact that even when physicians participated in ethics discussions, inside or outside the medical organizations, issues of ethics were dealt with predominantly *outside actual medical practice* in the problem-based committees—and framed as problems demanding, above all, a problem-solution constellation.

My train of thought here runs partially counter to views of the loss of the profession’s closure, mostly due to intruding foreign logics whittling away at ‘the medical ethos’ (see e.g. Sulilatu 2008; Vogd 2002). The ethos, however, can still be found, but less as a form of medical craftsmanship and more as pure scientific expertise backed up by recent results in highly specialized biotechnological research. For me, this currently serves as the foundation for constantly making closure in the medical profession.<sup>9</sup> This is by no means open-access knowledge, and, as stated before, it cannot be accomplished with standard formulas either; hence, some kind of professional magic remains also in the era of EBM.

Without a doubt, recent developments in bio-scientific research have produced novel demands for establishing the borders of medical care and its targets, for example, in the demarcation between life and death,<sup>10</sup> which potentially raises profound ethical issues in medical practice. On a general level these developments can be interpreted as relating to the tendency to increase so-called ‘non-knowledge’ (*Nichtwissen*). ‘Je mehr man weiß, desto mehr weiß man, was man nicht weiß’ (Luhmann 1991, p. 37). Medicine does not demarcate itself through the expansion of its store of knowledge, but instead, invariably finds itself at the forefront of new research and treatment possibilities. In regard to concrete medical practice, as stated before, non-knowledge also relates to the practical implementation of research findings: The discrepancy between the (vast) amount of knowledge potentially on hand and the lack of congruent embedding possibilities, as well as the skill and time to handle all this knowledge, constantly produce contingencies in decision making in hospitals and health care centres. To use EBM as a guide, instructions are needed. Medical sociologists Stefan Timmermans and Marc Berg (2003, p. 165), who base their empirical views on the impact of the growing amount of knowledge gained through EBM training, even state that ‘more EBM actually generates more uncertainty, less EBM often leads to a clearer practice’.

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<sup>7</sup> Ethics agencies are not the only ones on the receiving end of the emerging biomedical problems. In the case of foetal screenings, for example, parents carry the burden of particularly troublesome ethical decisions; medicine produces only (publicly expressed) value neutral information (Jallinoja 2002b; Helén 2004, p. 30–35).

<sup>8</sup> Various agencies that focus on medical ethics cover the whole field of medicine. They extend from the multifaceted, often legislation-informing, nationwide advisory boards (e.g. in Finland, the National Advisory Board on Social Welfare and Healthcare, ETENE) to intra-professional committees (the Committee for Ethical Matters of Principle of the Finnish Medical Association) to general forums (the Physicians’ Ethics Forum) to various intra-organizational commissions and more free-forming local discussions (see Lötjönen 1999; Fuchs 2005, p. 28–29; Halila 2003, p. 357–361; cf. Kappel 2008, p. 25–27 and Kettner 2005, p. 4–5). On the early stages of hospital ethics committees, see Rosner 1985.

<sup>9</sup> The symptoms of the scientific self-understanding of the medical profession is easily found, especially in efforts to close off all non-biomedical ways of healing from the medical sphere and from the focus on evidence-based diagnoses, treatment and prevention early on in medical training.

<sup>10</sup> 74 % of 344 American physicians who took part in a telephone interview stated that their last dilemma ending in ethical consultation was related to questions of the end-phase of life. These same dilemmas led to ethical consultations in every group of physicians interviewed. (DuVal et al. 2001 and 2004, cf. Saarni et al. 2008.)

Formulated in terms of systems theory, a drive towards a fact-dimensional primary logic of a profession can be distinguished. In current medicine, this core logic is first and foremost a science-coupled, duty-ethical justified *curing of diseases*, which is highly legitimated in modern society. The emphasis on (biomedical) science-based practice makes contingency reduction and exclusion from a-medical rationales more effective. On the other hand, the very same science connection enables the continued improvement and broadening of diagnoses, treatments and prevention methods, thus opening the doors to the (once) swollen contingency. Somewhat paradoxically, the logic of medicine—as medical science—might thicken, even though its scope is constantly widening.

My systems theory-informed argument can be summarized as follows: the a-medical issues, usually labelled ethical, are increasingly outsourced from medical practices simply because they are *a-medical*. Current evidence-based medicine, which more and more is being forced to observe other logics in its practice, is above all medicine that is based on medical science. Medical practice is thus primarily the fact-dimensional implementation of the sick/non-sick code, and this implementation is mediated and shaped by the standards and guidelines produced and backed by bio-statistical research. In working with patients, there is also an interactional aspect, ‘the humane level’ (Suomen Lääkäriitto 2005, p. 17) of the physician’s orientation. However, the possibility and probability of frictionless medicine implementation is maximized on occasions when no a-medical issue has to be taken into consideration: no economy, law or interactional patient or family and relative contacts; no a-medical problems often labelled ethical. This intensification is most likely in the context of medical organizations, above all, in the carefully divided wards of hospitals.

As an example of medical practice taking place on the fact-dimensional end of curative medicine implementation, consider an operation taking place in the surgical theatre of a central hospital. Other fact-dimensional logics have been effectively excluded by various, carefully deliberated organizational practices. Moreover, the social-dimensional factors have shrunk to a minimum, and sufficient time has been made as well by the organizational arrangements for the operation, although not necessarily from the point of view of the patient’s condition.

On the other end of the spectrum is a doctor-patient encounter in the general practice of a private health centre during which the patient complains of feeling downhearted and lonely. The time schedule is tight, with only a 15-min slot for each patient, including paper work. In any event the patient-customer has been investigating possible diagnoses and treatment possibilities on the Internet long before the encounter with the general practitioner. This occasion is far more contingent from the medical point of view, even though the contingency has been actively reduced through various factors that influence expectations, such as the spatial organization of the office, the waiting queue, clothing and use of language. Along with the goal of reducing sickness, there is at least the logic of economy in the form of a paying customer and this consumerism reduces the asymmetrical character of the encounter. In addition the patient’s symptoms, the strong social-dimensional load and the lack of time make the situation only partially medical in terms of sick/ non-sick implementation. From the vantage point of current medicine, the exclusion of these types of logics from concrete medical practice is of utmost importance. When all other issues are excluded, ‘entfaltet sich eine medizinische Praxis, die sich zunehmend nur noch auf eigentlichen performativen Aspekte ihrer Tätigkeit konzentriert: Die Zauberei des Heilens’ (Saake 2003, p. 456).

## **Ethics Organizations in a Society without a Centre: An Interactional Fix for an Impossible Task**

There is no integrative centre or top in the current societal form; none of its elements represents the (imaginary) whole, dictates the viewpoint or establishes all the expectations. From the vantage point of a theory of society, there is no guarantee of societal cement left for morality or religion, both of which

have been connected with individual lives and theories of academic reflection in the form of ethics and university theology. However, there seems to be a constant need for deliberating on more general, ethics-labeled problems and for defining issues with profound ethical ramifications (cf. Høyer 2008). In concrete considerations of various ethics organizations, ethics seems to be rather practical and partial, but as a (processual) mediator of mutually incommensurable logics rather than as a universal grounding or meta-rationale. The question is not about proving who is ultimately right morally, but, above all, it is about ‘wie verfahren werden soll, wenn in der Gesellschaft incompatible moralische Ansprüche konkurrieren’ (van den Daele 2001, p. 18).

These mostly problem-based processing practices have increased in biomedical research and practice in recent decades. Although the concrete workings and policies of various ethics committees may differ significantly, the common denominator can be found in how ethics issues are considered. Ethics dealt with and produced by committee differs clearly from philosophical ethics, whether in the form of practical ethics or more universal moral philosophy, and regardless of committee members’ education in the field of academic ethics (ibid., van den Daele 2008; Bogner 2009; also Saake and Kunz 2006). The question is more about decision-making practices, which are influenced—and also restricted—by various forms and contents of societal communication along with ethics. Thus, the ethics of ethics committees seems to be rather an ‘ethicalizing’ process connected with various procedures, tacks and etiquettes formal and informal, which function primarily as mediators between different positions. Armin Nassehi, Irmhild Saake and Katharina Mayr (2008, p. 134) speak about a gradually established, ‘unique form of communication [...], which of itself has taken on a kind of ethical quality’.

This ethical quality, emerging in the work of committees, does not achieve societal-wide resonance, however, if the communication cannot be moulded into a form that enables decision-making in practice. And it is the demand for just this kind of communication that strikes the imaginary agora of free ethical consideration and brings a host of organizational features to committee work. The result is most visible in regards to *temporality*. Time limits, related to all decision-making processes, are the worst enemy of (an illusion of) unrestrained consideration and deliberation. But there are also other forms in which the impossibility of amalgamating different views is embedded during committee meetings.

The essential starting point for committee work is the necessity of moderating the moral stances of the committee members. According to Wolfgang van den Daele (2001, p. 8–10), who has examined various ethical boards in Germany at length, this toning down is produced in *diskursiver Takt*: ontologizing tones of moralizing and deep personal convictions are framed outside the discussion in the practices of committee work (see also Bogner 2009). A shift from personal moral convictions to ‘the compulsions of society’ has to be made if the broader significance of ethical reasoning is to be a viable target. This shift is produced in committee practice through tact, discretion and respect, as well as through a general orientation to decision-making, which demands, above all, time limits. And ‘[e]xakt in diesem Sinne sind Ethik-Gremien Veranstaltungen zur *Verhinderung* von Moral und zur Generierung von Entscheidungen’ (Nassehi 2006, p. 375). There are, however, distinctions in the degree of this shift between different ethics organizations.

Issues considered a-medical and thus outsourced from the core of medical practice often have implications that reach far beyond their original context. This is one central feature of the a-medical nature of these issues; there is no medical ground or rationale on which they can be controlled or decided. The medical advantages of new technologies, for example, might be indisputable, but the ramifications, the concrete by-products, assumed risks and bafflement about the experience of blurred demarcations cannot be ‘medicalized’, and these kinds of issues are framed as ‘ethical problems’.

If these resonate strongly with *law communication*, for example, in the form of a compulsory ethical evaluation of biomedical research, then the case is clear: ‘ethical’ is that which is legal, and vice versa.

As Bijan Fateh-Moghadam, who has observed research ethical commissions from a jurisprudential point of view, writes together with sociologist Gina Atzeni (2008, p. 119): '[d]ie Bezugnahme auf Ethik soll in medizinrechtlichen Kontexten offenbar nicht von Moral unterscheiden, sondern vom Recht, als konkurrierendem normativen Bewertungsmaßstab'.

On the other hand, the ethics references of commissions dealing with research permits can be interpreted as potentially operating in competition with—or at least in a different way than—the legal references. This 'Renaissance der Ethik im Recht' (ibid., p. 120) is, however, a half-measure, because the dominance in society of a more deeply established law communication compared to philosophical or general ethical deliberation is clear, at least in *research ethical* agencies:

Die Arbeit von Forschungs-Ethik-Kommissionen besteht nicht in der neutralen, theoretisch-akademischen Reflexion über die Struktur moralischen Fragen und der auf diese in der Philosophie gegebenen Antworten, sondern in der handlungsleitenden Beratung und verbindlichen Entscheidung praktischer Fragen, die durch konkrete medizinische Forschungsvorhaben aufgeworfen werden. (Ibid., p. 117.)

The ethical consideration within these types of organizations with clear practical decision-making tendencies (applied permission 'approved' or 'declined') seems to be ethics rather in quotation marks: the practical bringing up of the matter in a commission is *performatively* 'ethical' *per se*. Most of those who attend the meetings of such organizations represent their own fact-dimensional expertise and professions (ibid, p. 132–140), and the dominance of law communication, for example, becomes obvious. In the work of strongly fact-related research ethical commissions, 'ethicality' shrinks in practice easily to the legal implementation of research permissions on hand, and the possibility of ethical consideration, be it more or less philosophical in nature, is automatically pushed to the margins (cf. Bora 2009).

This is also the point made by Klaus L. Høyer and Richard Tutton, who have observed language games with the ethics label in the context of the United Kingdom *Biobank* project. They speak of (2005, p. 386) "'ethics was here" ethics', a kind of ethical stamp of approval, which is a 'kind of assurance that potential or actual ethical problems have been identified, attended to and resolved'. Høyer's and Tutton's description of ethics, which bears a 'Kilroy was here' connotation, joins the same group of former 'ethics' characterizations, as 'empty ethics' or 'catwalk ethics', because 'the ethics encountered in these various biomedical contexts [...] involves little if any in-depth analysis' by 'academic standards' (ibid.). In the context of a more general university research ethics, Rebecca Boden, Debbie Epstein and Joanna Latimer (2009, p. 734) for their part speak of 'new ethical bureaucracies', which 'reduce and codify ethics into sets of highly scripted rules, procedures and behaviours'. Alfons Bora (2009, p. 18), for one, warns of an 'apolitical vacuum' produced by the process of legal-bureaucratic administration, which he calls the 'iron cage of law'. In the Finnish context Mianna Meskus (2009, p. 150), who has examined *problématiques* relating to the rise of medical genetics, stresses a critical view of research ethics as well and highlights the functionality of open ethics discourse for medical science. By demanding ethical discussions and ethical actions, we can be assured that a particular kind of medical research is regulated and collectively controlled, and this is often visible to a wider public as well. This type of highly *institutionalized* 'ethical consideration' and active informing about the work of such organizations in my view functions to *assure moral competence in biomedical research* and *as a source of information about the consideration of moral questions*, especially to wider publics (cf. Sulilatu 2008, p. 290).

Does the practice of ethical organizations that concentrate mainly on broad, principal issues differ from the practice of the above-mentioned law-dominated research permission commissions? On the basis of empirical observation of committee work in nation-wide boards and in the context of hospital operating committees, the answer is positive. The most explicit differences between these organizations and the research ethical commissions stem largely from the more open-ended nature of the issues

considered and from looser organizational regulations; in other words, there is a lower level of bureaucratization. There is thus more space—and often also a bit more time—for (ethical) considerations and reflection in general ethics committees. This does not mean, however, that the ethical character of boards and committees empty to academic-philosophical reasoning about the moral foundations of issues on hand. The question continues to be more about softening the edges of different perspectives, as well as about respecting different speaker positions and producing mutual symmetry in committee practice. A physician, lawyer, economist, Member of Parliament, ethicist, theologian and patient spokesman seems somehow to advance, despite the diverging starting points.

From a systems theoretical point of view, current societal form must proceed without a part or a logic capable of representing the whole, without an all-encompassing binding moral or universal ethics as its reflection theory. It is hard to imagine that a societal amalgamation, and especially one based on ethical reasoning, could be found in ‘a miniature form of society’ either. Ethics as an academic-philosophical reflection theory of morality cannot function—and as observed empirically, does not function—as the predominant and unifying form of communication in the practice of ethics committees and boards. Rather ethics is one potential chain of communication among others: medicine, law, economics or politics. The societal communication structure, fact-dimensionally differentiated though it be, does not dissolve into a single logic, likewise fact-dimensional, of ordering communication in the practices of ethics organizations, be this the logic of academic ethics or something else.

This fact of ‘undissolved’ societal differentiation implies that the ‘ethicality’ of ethics organizations is both fragile and local as well as temporal. Instead of a society-wide, all-encompassing fact-dimensional amalgamation, the matching of different logics takes place primarily in some other, possibly more fluid dimension. Ethics committees and boards are also part of society in the form of an *Organizationsgesellschaft* (Schimank 2005), and the (controlled) encounter of historically differentiated logics is largely possible in (only) organizational contexts. The constitutive characteristic of an organization, whether it be a global enterprise or an ethics committee, is to make decisions within certain limits based on time scarcity and the exclusion of non-members from the organizational processes; this activity plays a central role in binding the procedures of different fact-dimensional logics. The time frame and the exclusion make concrete decision-making possible.

But when the possibility of actual ethical deliberation is considered, *a fundamental contradiction in ethics organizations* emerges: On the one hand, the organizational procedures reduce the space of free (ethical) reasoning and discussion; on the other hand, unrestricted reflection does not resonate with the fact-dimensional logics of society at all. Ethical deliberation captures established parliamentary politics and legislation or medical practice only if it is compressed into clear decisions, statements and proposals for action. But the pressure of decision-making entails bureaucratization in the form of time limits as well as other structuring procedures and arrangements, all of which significantly restrict the space of free ethical discourse.

There is no way out of this ambivalence: On one side, there are highly resonating ‘rubber stamp commissions’, usually thoroughly determined by law communication; and on the other side, there are various forms of freely associating ethical discussion without hierarchies, time limits or pressures to make a binding decision—and, most importantly, without wider societal influence. This ambivalence in ethics organizations offers a perspective from which to observe the characteristics of ‘ethics’ inside committees and boards and paves the way for a search for the societal roots of this kind of empirical ethics.

Observed from a systems theoretical viewpoint, the main operation of ethics organizations is rather obvious: a resolution of fact-dimensionally incommensurable problems in social-dimensional interaction or, to be exact, *as* interaction. The interpersonal, symmetricizing interaction is embedded in

organizational arrangements and procedures, which enable the compression of a general ethical deliberation into societally more resonant forms, mainly through decisions, resolutions and recommendations. Hence, the organizational logic is the *sine qua non* of committee work, yet it limits a 'purer' and more fluid interaction.

The logic of organization is the logic of decision-making and to arrive at decisions, many kinds of demarcations and preparatory arrangements are required. These include matters involving personnel and the pre-filtering of material that ends up in the decision-making process, as well as, most remarkably, the control of time-dimensional pressures with precise time limits. The logic of interaction is—in the (systems) theoretical ideal form—the logic of face-to-face interaction. The time dimension in turn mainly appears chronologically: Only the concrete progress of discussion frames the interaction, and this happens on a sequential basis.

This kind of 'pure interaction' without the chaining of communication in societal systems at all is rather infrequent in the *official* dealings in the context of organizations. If a central function of ethics committees is to be sought, then my suggestion would be to make this kind of humane encounter possible. By this, I mean a kind of a 'humanizing' softening of the fact-dimensional differences, which would enable these historically differentiated logics to be dealt with in and during social interaction. And this is exactly the ethics of ethical organizations, not ethics as a philosophical reflection of morality, but '*ethischer Sensibilisierung*' (Saake and Kunz 2006; cf. van den Daele 2008; Bogner 2009) in the form of a contextual transition away from fact-dimensional biases towards an ethical encounter *rein als Menschen*—purely as a human being.

This kind of an interactional 'Etikett "Ethik" erzwingt hier explizit auch eine Akzeptanz nicht-sachlicher Formen der Argumentation' (Saake and Kunz 2006, p. 49). The contextual and temporal dissolution of societal expertise and thus the possibility of an interactionally respectful encounter is *the* ethical component of ethical committees and boards. *Ethics is first and foremost an ethicising practice, a practice which is ethical in itself, performatively.* In the parlance of functions, this possibility of temporary dissolution of societal fact-dimensional incommensurabilities is the 'function without functions' (Nassehi et al. 2008) of ethics committees and ethical boards.

If biomedical practice constantly produces an array of problems, some of them more ethical than others, and which cannot be resolved through the same logics by which they are produced—namely, the medical restoration of sick bodies—, then the question becomes where is a centre capable of amalgamating, even loosely, all the logics and rationales considered part of the context of today's polycentral society?

A systems theoretical answer, based on the observations of a constitutive form of current society, is simple: nowhere. The ethicality of ethical organizations is 'just' a small-scale reduction of fact-dimensional systems structure, a temporal and local, processual practice that constantly alternates between organizational dominance and interaction logics. This kind of practical ethicality dissolves the factual societal differentiation only for a brief moment in time and only partially—or illusorily. If the accomplishments of committee work are to have an impact outside committee meetings, then they have to be compressed into a somewhat resonating form: proposals for action, care guidelines, laws or payments. This demand, however, flattens out the role of free ethical consideration and funnels it merely to issues of fact. Freedom—with the power to influence—can be found between and within the combinations of these different logics and dimensions, hiding in indifference as required by the difference.

## References

- Armstrong, D. (2007). Professionalism, indeterminacy and the EBM project. *BioSocieties*, 2(1), 73–84.
- Ashcroft, R. E. (2004). Current epistemological problems in evidence based medicine. *Journal of Medical Ethics*, 30(2), 131–135.
- Bauch, J. (2000). Selbst- und Fremdbeschreibung des Gesundheitswesens. Anmerkungen zu einem absonderlichen Sozialsystem. In H. de Berg & J. Schmidt (Eds.), *Rezeption und Reflexion. Zur Resonanz der Systemtheorie Niklas Luhmanns außerhalb der Soziologie* (pp. 387–410). Frankfurt a. M.: Suhrkamp.
- Boden, R., Epstein, D., & Latimer, J. (2009). Accounting for ethos or programmes for conduct? The brave new world of research ethics committees. *The Sociological Review*, 57(4), 727–749.
- Bogner, A. (2009). Ethisierung und die Marginalisierung der Ethik. Zur Mikropolitik des Wissens in Ethikräten. *Soziale Welt*, 60(2), 119–137.
- Bora, A. (2009). Technoscientific normativity and the “Iron Cage” of law. *Science, Technology & Human Values*, 35(1), 3–28.
- van den Daele, W. (2001). Von moralischer Kommunikation zur Kommunikation über Moral. Reflexive Distanz in diskursiven Verfahren. *Zeitschrift für Soziologie*, 30(1), 4–22.
- van den Daele, W. (2008). Streitkultur. Über den Umgang mit unlösbaren moralischen Konflikten im Nationalen Ethikrat. In D. Gosewinkel & G. Folke Schuppert (Eds.), *Politische Kultur im Wandel von Staatlichkeit (WZB-Jahrbuch 2007)* (pp. 357–384). Berlin: Edition Sigma.
- DuVal, G., Sartorius, L., Clarridge, B., Gensler, G., & Danis, M. (2001). What triggers requests for ethics consultations? *Journal of Medical Ethics*, 27(1), 24–29.
- DuVal, G., Clarridge, B., Gensler, G., & Danis, M. (2004). A national survey of U.S. Internists’ experiences with ethical dilemmas and ethics consultation. *Journal of General Internal Medicine (JGIM)*, 19(3), 251–258.
- Evidence-Based Medicine Working Group. (1992). Evidence-based medicine: A new approach to teaching the practice of medicine. *The Journal of the American Medical Association (JAMA)*, 268(17), 2420–2425.
- Evidence-Based Medicine Working Group. (2002). *The users’ guide to the medical literature. Introduction: The philosophy of evidence-based medicine* (1A) (pp. 3–12). Chicago: The American Medical Association.
- Fateh-Moghadam, B., & Atzeni, G. (2008). Ethisch vertretbar im Sinne des Gesetzes—Zum Verhältnis von Ethik und Recht am Beispiel der Praxis von Forschungs-Ethikkommissionen. In S. Vöneky, C. Hagedorn, M. Clados, & J. von Achenbach (Eds.), *Legitimation ethischer Entscheidungen im Recht—Interdisziplinäre Untersuchungen* (pp. 115–143). Berlin: Springer.
- Fuchs, M. (2005). *National ethics councils. Their backgrounds, functions and modes of operation compared*. Berlin: National Ethikrat.
- Fuchs, C., Nagel, E., & Raspe, H. (2009). Rationalisierung, Rationierung und Priorisierung—was ist gemeint? *Deutsches Ärzteblatt*, 106(12), 554–557.



- Hacking, I. (1975). *The emergence of probability. A philosophical study of early ideas about probability, induction and statistical inference*. Cambridge: Cambridge University Press.
- Hacking, I. (1990). *The taming of chance*. Cambridge: Cambridge University Press.
- Hafen, M. (2007). *Mythologie der Gesundheit. Zur Integration von Salutogenese und Pathogenese (Mit einem Vorwort von Jost Bauch)*. Heidelberg: Carl–Auer–Systeme.
- Halila, R. (2003). The role of national ethics commissions in Finland. *Bioethics*, 17(4), 357– 368.
- Haug, M. R. (1988). A re-examination of the hypothesis of physician deprofessionalization. *Milbank Quarterly*, 66(Suppl. 2), 48–56.
- Helén, I. (2004). Technics over life: Risk, ethics and the existential condition in high-tech antenatal care. *Economy and Society*, 33(1), 28–51.
- Høyer, K. (2008). The ethics of research biobanking: A critical review of the literature. In S. Harding (Ed.), *The ethics of research biobanking* (Vol. 25, pp. 429–452). Nottingham: Nottingham University Press.
- Høyer, K. L., & Tutton, R. (2005). ‘Ethics was here’: Studying the language-games of ethics in the case of UK Biobank. *Critical Public Health*, 15(4), 385–397.
- Jallinoja, P. (2002a). *Genetics, negotiated ethics and the ambiguities of moral choices*. Helsinki: Kansanterveyslaitos.
- Jallinoja, P. (2002b). Ethics of clinical genetics. The spirit of profession and trials of suitability from 1970 to 2000. *Critical Public Health*, 12(2), 103–118.
- Jensen, U. J. (2007). The struggle for clinical authority: Shifting ontologies and the politics of evidence. *BioSocieties*, 2(1), 101–114.
- Kappel, K. (2008). National ethics advisory boards: Do they have a legitimate role in liberal democracy? In S. Lötjönen & H. von Troil (Eds.), *Bioethics, politics and business* (pp. 26– 44). Copenhagen: TemaNord.
- Kettner, M. (2005). Ethik-Komitees. Ihre Organisationsformen und ihre moralischer Anspruch. *Ervägen Wissen Ethik (EWE)*, 16(1), 1–16.
- Kristiansen, I. S., & Mooney, G. (Eds.) (2004). *Evidence-based medicine: In its place*. London: Routledge.
- Kruger, M. (2010). The ethical approach to evidence-based medicine. *South African Journal of Clinical Nutrition*, 23(1), 69–70.
- Liberati, A., & Vineis, P. (2004). Introduction to the symposium: What evidence based medicine is and what it is not. *Journal of Medical Ethics*, 30(2), 120.
- Lippman, A. (1991). Prenatal genetic testing and screening: Constructing needs and reinforcing inequities. *American Journal of Law and Medicine*, 17(1–2), 15–50.
- Luhmann, N. (1983a). Medizin und Gesellschaftstheorie. *Medizin, Mensch, Gesellschaft*, 8, 168–175.
- Luhmann, N. (1983b). Anspruchsinflation im Krankheitssystem. Eine Stellungnahme aus gesellschaftlicher Sicht. In P. Herder-Dorneich & A. Schuller (Eds.), *Die Anspruchspirale: Schicksal oder Systemdefekt?* (pp. 28–49). Stuttgart: Kohlhammer.

- Luhmann, N. (1990). Der medizinische Kode. In N. Luhmann (Ed.) *Soziologische Aufklärung: Konstruktivische Perspektiven (Band V)* (pp. 183–195). Opladen: Westdeutscher Verlag.
- Luhmann, N. (1991). *Soziologie des Risikos*. Berlin: Walter de Gruyter.
- Lötjönen, S. (1999). *Ethics committees in Finland—biomedicine and research*. Helsinki: The National Research Ethics Council of Finland, Ministry of Education.
- Mackie, J. L. (1974). *The cement of the universe: A study of causation*. Oxford: Oxford University Press
- Mayes, R. (2007). The origins, development, and passage of medicare’s revolutionary prospective payment system. *Medicine and Allied Sciences*, 62(1), 21–55.
- Meskus, M. (2009). *Elämän tiede. Tutkimus lääketieteellisestä teknologiasta, vanhemmuudesta ja perimän hallinnasta. (The science of life. A study of medical technology, parenthood and governing the heredity)*. Tampere: Vastapaino.
- Mol, A. (2002). *The body multiple: Ontology in medical practice*. Durham: Duke University Press.
- Mol, A. (2008). *The logic of care. Health and the problem of patient choice*. London: Routledge.
- Montori, V. M., & Guyatt, G. H. (2008). Progress in evidence-based medicine. *The Journal of the American Medical Association (JAMA)*, 300(15), 1814–1816.
- Nassehi, A. (2006). Die Praxis ethischen Entscheidens. Eine soziologische Forschungsperspektive. *Zeitschrift für Medizinische Ethik*, 52(4), 267–277.
- Nassehi, A., Saake, I., & Mayr, K. W. (2008). Health care ethics committees without function? Locations and forms of ethical speech in a ‘society of the presents’. In B. Katz Rothman, E. Mitchell Armstrong, & R. Tiger (Eds.), *Bioethical issues, sociological perspectives. Advances in Medical Sociology* (Vol 9, pp. 129–156). Amsterdam: Elsevier Ltd.
- Pelikan, J. M. (2007a). Understanding differentiation of health and modernity by use of sociological systems theory. In D. V. McQueen, I. Kickbush, L. Potvin, J. M. Pelikan, L. Balbo, & T. Abel (Eds.), *Health and modernity. The role of theory in health promotion* (pp. 74–102). New York: Springer.
- Pelikan, J. M. (2007b). Zur Rekonstruktion und Rehabilitation eines absonderliches Funktionssystems —Medizin und Krankenbehandlung bei Niklas Luhmann und in der Folgerezeption. *Soziale Systeme*, 13(1 & 2), 290–303.
- Pelikan, J. M. (2009). Ausdifferenzierung von spezifischen Funktionssystemen für Krankenbehandlung und Gesundheitsförderung oder: Leben wir in der „Gesundheitsgesellschaft“? *Österreichische Zeitschrift für Soziologie (ÖZS)*, 34(2), 28–47.
- Ritzer, G., & Walczak, D. (1988). Rationalization and deprofessionalization of physicians. *Social Forces*, 67(1) 1–22.
- Rosner, F. (1985). Hospital medical ethics committees: A review of their development. *The Journal of the American Medical Association (JAMA)*, 253(18), 2693–2697.
- Saake, I. (2003). Die Performanz des Medizinischen. Zur Asymmetrie in der Arzt-PatientenInteraktion. *Soziale Welt*, 54(4), 429–460.
- Saake, I., & Kunz, D. (2006). Von Kommunikation über Ethik zu “ethischer Sensibilisierung”: Symmetrierungsprozess in diskursiven Verfahren. *Zeitschrift für Soziologie*, 35(1), 41–56.

- Saake, I., & Vogd, W. (Eds.) (2008) *Moderne Mythen der Medizin. Studien zur organisierten Krankenbehandlung*. Wiesbaden: VS Verlag für Sozialwissenschaften.
- Saarni, S., Halila, R., Palmu, P., & Vänskä, J. (2008). Ethically problematic treatment decisions in different medical specialties. *Journal of Medical Ethics*, 34(4), 262–267.
- Sackett, D. L. (2002). Clinical epidemiology: what, who and whither. *Journal of Clinical Epidemiology*, 55(12), 1161–1166.
- Schimank, U. (2005). Organisationsgesellschaft. In W. Jäger & U. Schimank (Eds.), *Organisationsgesellschaft. Facetten und Perspektiven* (pp. 19–50). Wiesbaden: VS Verlag für Sozialwissenschaften.
- Self, D. J., Skeel, J. D., & Jecker, N. S. (1993). A comparison of the moral reasoning of physicians and clinical medical ethicists. *Academic Medicine*, 68(11), 852–855.
- Stollberg, G. (2009). Das medizinische System. Überlegungen zu einem von der Soziologie vernachlässigten Funktionssystem. *Soziale Systeme*, 15(1), 189–217.
- Sulilatu, S. (2008). Klinische Ethik-Komitees als Verfahren der Entbürokratisierung? In I. Saake & W. Vogd (Eds.), *Moderne Mythen der Medizin. Studien zur organisierten Krankenbehandlung* (pp. 285–306). Wiesbaden: VS Verlag für Sozialwissenschaften.
- Suomen Lääkäriliitto (2005). *Lääkärin etiikka. (Physician's Ethics)*. Helsinki: Suomen Lääkäriliitto.
- ten Have, H. A. M. J. (2001). Genetics and culture: The 'geneticization thesis'. *Medicine, Health Care and Philosophy*, 4(3), 295–304.
- Timmermans, S., & Berg, M. (2003). *The gold standard. The challenge of evidence-based medicine and standardization in health care*. Philadelphia: Temple University Press.
- Timmermans, S., & Kolker, E. (2004). Evidence-based medicine and the reconfiguration of medical knowledge. *Journal of Health and Social Behaviour*, 45(1), 177–193.
- Timmermans, S., & Mauck, A. (2005). The promises and pitfalls of evidence-based medicine. *Health Affairs*, 24(1), 18–28.
- Vineis, P. (2004). Evidence-based medicine and ethics: A practical approach. *Journal of Medical Ethics*, 30(2), 126–130.
- Vogd, W. (2002). Professionalisierungsschub oder Auflösung ärztlicher Autonomie. Die Bedeutung von Evidence Based Medicine und neuen funktionalen Eliten in der Medizin aus system- und interaktionistischer Perspektive. *Zeitschrift für Soziologie*, 31(4), 294–315.
- Vogd, W. (2005). Medizinsystem und Gesundheitswissenschaften—Rekonstruktion einer schwierigen Beziehung. *Soziale Systeme*, 11(2), 236–270.
- Worrall, J. (2010). Evidence: philosophy of science meets medicine. *Journal of Evaluation in Clinical Practice*, 16(2), 356–362.