

## Short literature notices

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Havi Carel.: 2016, *Phenomenology of Illness*. Oxford: Oxford University Press. 272 pages. ISBN: 978-0199669653. Price: £30.00.

In 1930, Virginia Woolf remarked that ‘considering how common illness is, [...] it becomes strange indeed that illness has not taken its place with love and battle and jealousy among the prime themes of literature’ (On Being III). Havi Carel starts with a similar observation, namely that given the great public interest in illness—Thomas Laqueur has recently described our age as the ‘golden age of pathography’ (London Review of Books, 2016)—philosophy seems to have largely bypassed the experience of illness. Carel finds this as troubling, not only because ‘philosophy is necessary for a full understanding of illness’ (p. 2), but also because illness can ‘illuminate philosophy’ (p. 205). In her thought-provoking study, she therefore proposes that phenomenology is particularly suited for an exploration of the ‘philosophical potential of illness’ (p. 15) and her meticulous readings of Merleau-Ponty, Sartre, Husserl and Heidegger, among others, convincingly make the case that these thinkers allow for fresh perspectives on the ‘lived experience’ of disease, which is illness (p. 1).

Phenomenology of Illness falls into two parts: The first four chapters set out to introduce and explore the theoretical framework, while Chaps. 6–10 are drawing on this framework in order to question how this relates to more concrete examples and topics of general philosophical interest, such

as, for example, epistemic injustice in healthcare and the relationship between illness and death. These two parts are fittingly separated by, to borrow Michael Bury’s term, a ‘biographical disruption’, namely a chapter on the phenomenology of breathlessness (‘Chronic Illness as Biographical Disruption’, *Sociology of Health and Illness*, 1982). Carel is perhaps strongest when her writing draws on her own experience of living with Lymphangioleiomyomatosis (LAM), in order to claim that breathlessness cannot be understood ‘solely as a symptom’, but must be read as both a ‘a limiting factor, and a condition of possibility’ for the person affected by it (p. 128). This captures Carel’s original perspective in this book: her reading of illness as a series of interconnected losses, which she bases on Kay Toombs and juxtaposes to the ‘hidden and often surprising positive effects illness may have on the ill person and those around her’ (p. 130). Questioning the transparency of the healthy body and arguing that a good and happy life is possible with illness, Carel is however cautious to not advance a redemptive or romantic account of illness, and importantly highlights that not every experience of illness will have edifying effects.

Running through this study is a critique of the ways in which modern society, and medical ethics in particular, has put ‘such a premium on autonomy and independence’ (p. 77), which Carel claims explains our troubling relationship with illness, as it reveals to us that we are ‘dependent upon others and therefore need both trust and respect’ (p. 77). This, she links to Alasdair MacIntyre’s argument that a recognition of our vulnerability would be ‘a precondition for a style of moral philosophizing attentive to the human condition’ (p. 225), and *Phenomenology of Illness* can be seen as a step into that direction. This leads her to draw on an impressive range of references in philosophy, bioethics and medicine, which her clear and succinct prose makes easily accessible. The sheer breadth of her scholarly study

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might also explain why at times one might have expected a more extensive analysis of some concepts mentioned in passing, such as, for example, empathy, disability or Can-guillhem's definition of disease. But in a sense the real aim of the study lies beyond these contextualizations and in the more ambitious goal to unsettle the separateness of Susan Sontag's kingdom of the well and kingdom of the ill, given that 'we all begin in complete dependence on others and we mostly end there' (p. 227). The personal vignette, with which she closes the book, powerfully captures the idea that this recognition of interdependence experienced in illness makes for a different kind of philosophy, one that is 'all-consuming, extreme, and terrifying' (p. 224). Carel's exceptional and moving study will indubitably be seminal in motivating this much-needed shift in thought.

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Sándor J.: 2016, *Az én molekulám: Bioetika és emberi jogok a XXI. század elején*, Budapest, Hungary, L'Harmattan Kiadó, 228 pages, ISBN: 978-963-414-223-2. Price: 2366 HUF.

## My molecule

Bioethics and human rights in the beginning of the twenty-first century is the new book of Judit Sándor, who is a full professor at the Faculty of Political Science, Legal Studies and Gender Studies at the Central European University, Budapest, and a founding director of the Center for Ethics and Law in Biomedicine at this University. Reading the title of the book, it seems to me that it is about analyzing the topic only in a theoretical way, but after the first couple of pages I realized that the author also attempts to illustrate the topic with some practical examples. What is truly new and remarkable about Judit Sándor's book is that she analyzes the bioethical issues from a human rights perspective, and it is significant because there has never been any Hungarian work written in this topic in that comprehensive way.

According to the author, the current issues of bioethics extend far beyond the relationship between doctors and patients, the patient's rights or euthanasia, and this is the reason why she analyzes new biotechnological issues like genetic research, biobanks, reproductive processes or stem cell research from a human rights-based approach. In the first part of the book the author examines the most important international organizations which deal with bioethical issues through human rights regulations. She discusses UNESCO's and the UN's global activity in relation to biomedicine, and she introduces the most important European regulations about the topic. After reviewing the theoretical background

of the question and the most important elements of contemporary biopolitics, in the second part of the book, from chapter to chapter, she examines the question of reproductive rights and she analyzes the rules of the in vitro fertilization process and the status of embryos in biomedical research. The author provides a comprehensive analysis of legal cases before national and international courts, gently explaining her own position, which also motivates the reader to form an opinion about these controversial questions.

There are some other questions discussed in the book: What are the effects of biotechnological research on society and legal regulation? What legal and ethical norms could apply to human DNA, molecules, embryos or human gametes? According to the author, it is time to admit that these issues create intermediate legal norms: "they are partly regulated by the human rights of the person [...] and, on the other hand they covered by the biotechnological rules of a new specific area as they undergo changes in research and biotechnological processes." Having read this book we may see the clear relationship between human rights and bioethical issues, even if not solving all of the problems listed in the book, but at least we probably try to make our own judgment about the topic. As Judit Sándor comes to her final conclusion "A multidisciplinary approach is needed to interpret and protect the techno-centric human of the 21st century, both molecularly and personally."

Diversified and complex knowledge is needed to build the book in this way, and due to the fact that the issues of bioethics are directly related to individuals' everyday life, it was a great idea to write this book not only to doctors, researchers or lawyers, but for the wider public too. The book is also an enjoyable reading and the cases included in make it more interesting. The author successfully avoids lengthy philosophical explications, so the book is a highly recommended reading for a wide audience.

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O'Mathúna, D., Gordijn, B., Clarke, M. eds.: 2014, *Disaster Bioethics: Normative Issues When Nothing is Normal*. Dordrecht: Springer, 219 pages. ISBN: 978-94-007-3863-8. Price: 48 EUR.

The Haiti earthquake, the Fukushima nuclear incident, the Sri Lanka tsunami and the 9/11 terrorist attacks—all of them somewhat different, yet all share a common feature: Laymen and professionals alike remember them as archetypal examples of a notion we unfortunately need to face more and more often—disasters. And though it is beyond doubt that disasters—let them be natural or man-made ones, one affecting a "well ordered" and well-equipped society or a community in a resource-poor and "developing" area—are

coeval with our civilization, yet, the ever faster development of medical means of humanitarian and catastrophe relief in our globalized world raise ever newer ethical dilemmas. This applies to all kind of actions involving human subjects that take place in disaster struck environments regardless of whether they are of biomedical, psychological sociological sort, or whether their main end is to respond to the health-care needs of the population in need or to conduct research aiming to produce generalizable knowledge for improving future operations.

Therefore, the main purpose of this great little volume is to provide both theoretical outlines and practical guidance (even policies) for those concerned with this recently emerging and quickly evolving field. This book will be of enormous assistance for a quite diverse set of people: field workers (physicians, psychologists, social workers and humanitarian helpers), medical students and lecturers, various stakeholders in research and humanitarian organizations and NGOs—whether taking part in supporting the population with health care aid or be more concerned with the research side of disaster response.

The volume, consequently, is divided into two parts: The first one contains writings on the numerous (and subsequently diverse) issues of medical ethics occurring in the context of providing aid for health-related needs (like Schwartz et al.'s writing) or psychological support (e.g. Sumathipala's article) in disaster situations. The topics of this session are ranging from more theoretical issues (for instance Ahmad et al.'s and Ten Have's seminal analyses) to more practical (see Barilan et al.'s examination of triage-strategies) ones; from general questions (like the introductory chapter) to much more particular issues (which is nicely exemplified by Scanlon's paper on the role of media in such cases).

The second part—the chapters concentrating on the ethical aspects of conducting research in disaster settings—also contains a diversity of approaches to the subject matter. Here one also can look for more conceptual investigations (take for instance Shuster's or Annas's examinations) and for others attempting to provide very pragmatic guidelines and analyses that could be especially exciting for those aiming to take part in research conducted in disaster-related contexts.

On the top of it, both part's writings address some fundamental questions or dilemmas stemming from the notional difficulties of these particular bioethical issues: How could one define 'disaster' at all? Should one than attempt to create new guidelines particularly addressing these situations? Are there special research ethical norms that should pertain in such research scenarios? Or, to take an even more fundamental, basic question—what considerations could justify to conduct research on human participants at all in such extreme circumstances which both the professional community and the layman regard most commonly as ones where

relief should be the first (and due to some voices: maybe the only) priority?

The reader will find answers (but at least very well circumscribed questions and suggestions) not only to these fresh and exciting questions, but attached to the above mentioned writings will she find an appendix containing two guidelines (one from the International Red Cross and Red Crescent Movement and NGOs and another from the WMA). This volume is certainly addressing the uneasy question of what ethical considerations should be addressed when—as the subtitle suggests—"nothing is normal".

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Gigerenzer, G., Gray, J.A. Muir.: 2011, *Better Doctors, Better Patients, Better Decisions—Envisioning Health Care 2020*. Strungman Forum Reports, Cambridge, MA: MIT Press. 391 pages, ISBN: 978-0-262-51852-9. Price: 22 USD.

This is neither a philosophy book, nor a book of bioethics. Still a highly relevant book for all of those experts who have an intellectual interest in health care related fields. As the subtitle also indicates—*Envisioning Health Care 2020*—the volume was created with an intention to put together ideas about the future of medicine and identify the ways it can be made better. According to the editors and contributors of the book health care could be made less harmful and more patient centered with the general improvement in health literacy. The numerous contributors of the volume—more than 40 leading experts from a variety of health sciences research and implementation areas—are reflecting on the various aspects of health literacy.

As it was shown in an earlier book of Gigerenzer (*Calculated Risk*), both doctors and patients understanding of statistical terms, representations, and calculations, are significantly deficient. In light of the wide usage and fundamental effect of statistics in contemporary medical decision-making this deficiency should be seen as a rather alarming fact. Patients does not understand percentages, doctors are often misled by relative risks and journalists present data in obscure ways. Risk illiterate doctors and patient are making decisions that are often leading to harmful and unwarranted medical interventions. What this book adds to these earlier insights on risk illiteracy? The previous book was a single author volume that presented risk illiteracy for a lay audience and attempted to teach the ways how to overcome it in our individual lives. The current volume has more a health policy perspective on how to improve health literacy in our modern societies and offers a rich variety of expert comments on the same challenge: statistician, hospital doctor, experimental psychologist, technology and quality assessment, journalist etc. Some chapters of the book focus on investigating the roots of the problem of health illiteracy,

like Nelson's contribution gives us a good overview on funding of health research and its consequences, and some chapters are written by multiple authors with a focus on identifying the major barriers of proper health information. The last section of the volume with its six papers is facing the future with attempting to identify the major tools of change in the various dimensions of evidence base, drugs and informed decisions, medical education, medical decision-making. The last paper is a manifesto for change: with asking the question: How will health care professionals and patients work together in 2020? In their attempt to accelerate a shift in a new paradigm of patient centered health care they are highlighting some practical steps within and outside the

complex systems of modern health care that could support their initiative.

In sum, this is well edited important book with a highly relevant topic that shows the need for health literacy in modern societies, and proves that that it should form an explicit part in health care reforms. Thus, the book could generate interest in all those who are working for a better health care, be there doctors, researchers, policy makers, bioethicists, or health economists.

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