

EACME Newsletter

European Association of Centres of Medical Ethics

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¹ B. Pascus “Measles cases in 2019 have already exceeded all of 2018” CBS News 1st April 2019
<https://www.cbsnews.com/news/measles-outbreak-2019-exceed-2018-numbers-anti-vaccination/>

² D. Lee “Google announces AI ethics panel” BBC News 26th March 2019
<https://www.bbc.co.uk/news/technology-47714921>

EDITORIAL

Several items in the news recently may have caught your attention as they have mine: there has been disquiet about the role of social media in recent outbreaks of preventable disease worldwide due to anti-vaccination campaigns;¹ there have been questions about the roles and constitution of industry ethics committees convened to govern “artificial Intelligence ethics”;² more broadly the protests at the pace of action over climate change by schoolchildren have also hit the headlines.³ These social phenomenon may be linked. The same technologies increase the effectiveness of anti-vaccination campaigns as power climate change activism. The heuristics of these technologies are frequently driven by the same artificial intelligence technologies that industry ethics committees are intended to police. Whether industry bodies, at best answerable to their shareholders, have sufficient public accountability is heatedly questioned. Yet these questions do not just affect the tech-giants. The same questions about public role and accountability are also true of medical ethicists, whether working within hospitals or in academic roles. Should we be answerable for the opinions we express in the clinic, the classroom or the academy? Should we seek to neutralise our own intuitions and perspectives? Or should we embrace them and become activists in our areas of (presumptive) expertise? The Janus faces of activism highlighted here show there is surely a need both for passion and disinterested expertise — so, on what authority do we, as ethicists, express our viewpoint

³ Reuters “Climate strikes: Students in 123 countries take part in marches” 15th March 2019
<https://www.euronews.com/2019/03/15/climate-strike-school-students-from-over-120-countries-march-to-change-history>

— or silence our consciences? These are important questions for medical ethicists in every sphere.

In this month's newsletter we consider the ethics of new technologies and climate activism, in the form of two excellent articles by, respectively, Johanna Hovemann and colleagues and by our stalwart contributor Dr. Jean Martin. Alongside these is a very interesting article examining the ethical implications of austerity, an essay by the editors of a major new collection on migrant health and book reviews of both this collection and a new work on examining the relationship of law to psychiatric practice. I hope, to use an English idiom, there will be "grist for your mill" in pondering these questions in this issue of the EACME newsletter.

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NEWS FROM THE EACME BUREAU

Dear EACME Members,

We hope this Newsletter finds you well.

Here at the EACME Bureau things have been going very well since the last Newsletter. We are very proud to let you know that this year's conference preparations are advancing well. The Ethox Centre and the Wellcome Centre for Ethics and Humanities in Oxford received a very high number of abstracts (about 180) which will be reviewed in the next weeks. We would like to thank everyone who submitted an abstract, and everyone who has already signed up – those who have not registered yet, don't forget to sign up soon to benefit from the Early Birds fee! We do not have a final programme yet but we are very excited to announce the confirmed key-note speakers at our Oxford conference: Nikola Biller-Andorno, Tom Shakespeare, Annelien Bredenoord and Richard Ashcroft, together with your contributions, will contribute to a high quality and diverse programme!

Furthermore, we have already started planning the next annual conference which will take place in Cluj, Romania, in 2020. At the end of June, the Bureau will travel to Cluj to meet Maria Aluas and her team. We will discuss the conference themes and possible key-note speakers as well as visit the venue. We look forward to preparing the next conference and will keep you updated about our progress in the next Newsletter!

For now we hope you enjoy reading this Newsletter.

With best wishes,

Ruth, on behalf of the Bureau (Rouven, Bert and Angelique).

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AGING BETWEEN PARTICIPATION AND SIMULATION – ETHICAL DIMENSIONS OF SOCIALLY ASSISTIVE TECHNOLOGIES

International Conference for Young Scholars

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1. Introduction

Demographic changes lead to major challenges in European healthcare systems. An increasing number of elderly people will have to be provided with different kinds of health services. To an equally growing extent, these people will be limited in their motor, sensory, cognitive or social skills due to morbidity or as a result of normal aging, and are thus dependent on help in social participation to achieve personal goals or to maintain their everyday activities. At the same time, family and social structures are changing. Rising employment rates, an increase in personal mobility and changing family structures will lead to an overall smaller share of health care providers in relation to persons dependent on care. The scarce resources of European healthcare systems will no longer be sufficient to cover all needs at the same time. Socially assistive technologies such as robot companions, smart screen assistants or GPS-trackers promise to mitigate these tensions in healthcare systems. Their use may preserve individual rights by supporting the elderly in their daily environment, by offering emotional as well as physical care and support or by providing relief and assistance for healthcare professionals. However, socially assistive technologies raise difficult ethical questions. These devices integrate into the social sphere by simulating "social behaviour", use of facial expression detection, artificial intelligence or autonomous learning algorithms. Increasing resemblance of machine reaction patterns and human behaviour might add to the aim of a further integration of supportive technology in everyday surroundings. It, however, contains the risk of deceiving users, manipulating their behaviour or might even lead

to a replacement of human healthcare workers or caring relationships.

Joschka Haltaufderheide, Johanna Hovemann, Corinna Jung, Ina Otte and Jochen Vollmann invited twelve young scholars for the conference “Aging between Participation and Simulation – Ethical Dimensions of Socially Assistive Technologies” held from 4 February to 8 February 2019 at the Institute for Medical Ethics and History of Medicine at Ruhr University Bochum to discuss the tipping points between ethical and unethical use of socially assistive technologies in healthcare. The aim was to initiate an interdisciplinary ethical discourse on socially assistive technologies to identify practically relevant, ethical areas of tension and to outline further developments in the field. The conference was generously funded by the ELSA-funding initiative (Ethical, legal and social aspects of modern life sciences) of the German Federal Ministry of Education and Research (BMBF), which is concentrating on the impacts of life sciences on our society and aims to connect young scholars from different disciplines and countries. The funding included all costs of the five day conference such as travel reimbursement, accommodation, catering or honorarium for contribution.

2. Organizing the discourse

The Institute for Medical Ethics and History of Medicine in Bochum has a long tradition in hosting conferences for young scholars. Following our predefined organizational scheme, the call for abstracts was released four month prior to the conference. All submissions went through a careful reviewing process putting weight on originality, novelty and interdisciplinary aspects of the contributions. Twelve participants were selected representing a variety of disciplines ranging from philosophy, nursing science, law, economics, social and educational science. Due to the funding, we were able to invite seven national scholars from different universities throughout Germany and five international scholars from Italy, Switzerland, Spain, Sweden and the Netherlands. Since one of the aims of this conference was to initiate an interdisciplinary discourse and to create a dense working atmosphere young scholars would benefit from, the participants’ contributions were supplemented by several lectures and workshops by renowned experts in the field, and a public lecture.

2.1. Expert lectures and workshops

With his keynote lecture “Assistive Technologies in the Mirror of Technology Assessment” Michael Decker from Karlsruhe Institute of Technology set the stage for a week of intensive discussions. Decker gave an overview on current technological developments. He

critically commented on the gap between funding agendas and insights from needs-based technology assessment and directed attention to the importance of ethically informed frameworks for responsible research and innovation. Jochen Vollmann and Joschka Haltaufderheide completed this general overview with two workshops on ethical, legal and social foundations of the discussion and on the situation of elderly people as a vulnerable group in healthcare. The importance of the difference between social assistive devices as replacement technology and supportive technology to existing human caring relationships was made clear by Margaretha Halek and Claudia Dinand from the German Center of Neurodegenerative Disease, Witten. They underlined the value and complexity of informal caring relationships between humans from the perspective of nursing sciences by giving a video analysis of daily caring situations with dementia patients in informal care settings. In an expert lecture, Uwe Johannson and Jaqueline Geisler from LWL Hospital Dortmund gave an overview on their attempts to use the robotic seal Paro in gerontopsychiatric settings. From a clinician’s perspective Johannson and Geisler pointed out how the device was implemented and gave an overview on their impressions and experiences on a years-long use of Paro. Finally, Hartmut Remmers from the University of Osnabrück (nursing science) gave a public lecture on technical utopias and political illusions in development of social assistive technologies. Remmers demonstrated that an increasing implementation of technology in the healthcare system should lead to a change in dealing with the competitive allocation of funds. There needs to be a paradigm shift from a technology-focused politics to a social and health politics. More than 50 Bochumer fellow citizens came to listen to his talk “technical utopia – political illusion?” and closed the session with a lively discussion.

2.2. Participants’ contributions

Shabahang Arian (Pisa) started the conference week on the participants side. Drawing on the distinction of care and cure, she discussed general boundaries of caring robots in elderly care and analyzed different ways of ethical assessment of socially assistive devices in ethical theory and law with a focus on the difference between substitutional use of technological device and support of existing human caring relationships. Following this general perspective Svenja Wiertz (Tübingen) referred to the notion of trust as an important concept to capture differences between human-to-human and human-machine relations. Trust, Wiertz argued, can be conceptualized as accepted vulnerability and is an important part of human relationships while it is not possible to trust technical devices.

Insights on existing applications and projects currently under development were given in the following

three contributions. Anna Hauptelshofer (Osnabrück) reported on attempts to promote e-health literacy by combining the e-health application “FeelFit” and the concept of a digital nurse. She presented an integrated use-case to discuss necessity of need-oriented technologies and digital competencies as integrated part of education in nursing. Amelie Altenbuchner (Regensburg) discussed opportunities and challenges of motion tracking systems in hip-fracture rehabilitation. Continuous, individualized and objective measurement of rehabilitants recovering from a hip fracture might yield important insights for the development and adjustment of therapy, but aspects of data protection and protection of privacy need to be weighed also. Angelika Schley’s (Lübeck) presentations referred to the ACTIVATE-project which aims to develop and implement a socio-technical system to improve care for critically ill adults under-going weaning from the mechanical respirator in critical care settings. She showed how the socio-technical arrangement can be critically assessed using the well-known MEERSTAR-model to improve it and to take into account the situation of vulnerable patients in critical care.

Sarah Palmdorf (Bielefeld), Christoph Schneble (Basel) and Julia Hoppe (Paderborn) connected to the theme of a needs-driven development of technology by providing important insights on attitudes, wishes and behavior of users in different contexts. Sarah Palmdorf explored the needs and demands towards technical devices of people with dementia in home care settings. Attitudes in this population were shown to be largely shaped by weighing of values such as privacy vs. safety which is often ignored in formal risk assessments of technology. Referring to the example of a GPS-motion tracker, Palmdorf showed how one might include ethical considerations and central value conflicts of stakeholders into technical assessment in different contexts. Christophe Schneble reported results of a study on challenges and opportunities in digitalized healthcare in Switzerland. As Schneble showed, some of elder peoples’ wishes and attitudes towards the use of socially assistive technologies can be used as predictors of adoption of technology and should be integrated in a needs-driven development of technology. Julia Hoppe analyzed stakeholder expectations towards robotic technology in elderly care. Hoppe pointed out that stakeholders, relatives and caregivers might have considerably different expectations. However, a majority puts weight on the essential differences between the quality of human relationships compared to technological options.

In addition, some contributions challenged classical ethical concepts in regard to their applicability in technology settings. Based on the example of a mobile support system for behavior change, Iris Loosman (Eindhoven) showed that this may include to rethink

traditional concepts such as informed consent to make them applicable to the digital world. Alternatives could be models of distributed consent, won by learning from developments in clinical care and analysis of the function of consent. Bettina Schmietow (Munich) mapped the shifts of autonomy as one of the core concepts in digitalized healthcare. Contextual adjustments of this concept may enrich the conceptualisations and assessment of technologies alongside established ethical frameworks, and would ideally be tested out in a further step as part of an empirical ethics scenario. From the perspective of law, Ricardo Morte Ferrer (Granada) added to this topic by illustrating the shifts in autonomy and data protection law in Europe. According to Morte Ferrer, these regulations should have the essential goal to protect affected individuals asymmetric power relations which emerge as a result of digitalized economy. The effective protection of the personal autonomy of the elderly and disabled people might be focused there. Finally, Björn Lundgren (Stockholm) widened the debate by drawing attention on the differences between a reactive approach of ethics which is concerned with already existing technologies, their assessment and improvement and pro-active ethics concerned with reacting to possible future developments. In regard to the latter, Lundgren analyzed possible implementations of augmented AI-Memory-technologies and outlined risks and threats stemming from their further development.

3. Conclusion

Initiating interdisciplinary discourse on new topics is essential in medical ethics. During our conference “Aging between Participation and Simulation – Ethical Dimensions of Socially Assistive Technologies”, we aimed to develop such a discourse on opportunities and challenges of socially assistive technologies in healthcare. The conference gave an overview on the tipping points of the discussion on socially assistive technologies. The aim to create a fruitful interdisciplinary discourse has been reached through a controversial dialogue between all participants and experts. The received feedback was consistently positive, especially the interdisciplinary discourse and organizational work was confirmed through very good appraisals. Contributions to the conference as well as its results will now undergo careful revisions and will then be published as open access conference volume within the next year.

As organizers, we appreciated the presence of such an open and ambitious group of young scholars and experts as well as the lively debate and dialogue. We will continue to provide opportunities for collaboration on the topic and will strive to maintain the dialogue. Although especially organizational demands in this kind

of conferences might be high we think the intense working atmosphere, international exchange on a European level and the opportunity to substantially contribute to a novel topic for young scholars is worth the effort.

Conference team:

Dr. phil. Joschka Haltaufderheide / Johanna Hovemann, M.A. / Dr. sc. med. Ina Otte, Dipl. Soz. / Prof. Dr. med. Dr. phil. Jochen Vollmann from the Institute for Medical Ethics and History of Medicine, Ruhr-University Bochum & Dr. phil. Corinna Jung from the Thorax Clinic at the Heidelberg University Hospital (scientific head oncology)

Senior researchers and experts:

Prof. Dr. rer. nat. Michael Decker (Karlsruhe) / JProf. Dr. rer. medic. Margareta Halek (Witten) & Claudia Dinand (Witten) / Dr. Uwe Johansson (Dortmund) & Jacqueline Geisler (Dortmund) / Prof. Dr. phil. habil. Hartmut Remmers (Osnabrück)

Young scholars:

Amelie Altenbuchner (Regensburg), Shabahang Arian (Pisa), Anna Sophie Haupeltshofer (Osnabrück), Julia Hoppe (Paderborn), Iris Loosman (Eindhoven), Dr. Björn Lundgren (Stockholm), Ricardo Morte Ferrer (Granada), Sarah Palmdorf (Bielefeld), Angelika Schley (Lübeck), Dr. Bettina Schmietow (München), Christophe Schneble (Basel), Svenja Wiertz (Tübingen)

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PROJECT SUMMARY - THESIS

Health under austerity in Europe – Ethical considerations

Developments in several EU countries such as Greece, Spain or Portugal have shown that the economic crisis, that started in 2008, had and still has an adverse impact on social arrangements, and as a result particularly on

the health of citizens. Striving for economic recovery, governments of the above-mentioned countries were required by the so-called Troika to implement austerity measures. Yet, austerity measures are not only highly contested by economists. They also potentially come into conflict with justice, equity and solidarity – values that are considered to be central to the European Union including its health systems.

The objective of my PhD project (Maastricht, 2018) was to discuss those consequences of austerity and scarcity resulting from the economic crisis of 2008 on health in European and particularly EU contexts by taking an ethical perspective.

Impact of austerity on health and health care provision: applying consequentialist and deontological approaches

First, I assessed existing knowledge about the consequences of austerity measures resulting from the economic crisis by applying distinct ethical theories, specifically the 'capabilities approach of justice' (CA) by Amartya Sen (stemming from the consequentialist realm) and the Bioethical Imperative by Fritz Jahr (representing a deontological theory) in juxtaposition to the often used consequentialist principle of 'first do no harm' introduced parenthetically as an ethical criterion by austerity and health researchers Stuckler and Basu. The assessment applying the CA showed that health outcomes were and are impacted in a negative way, not only in terms of adverse effects on equality of opportunity to gain or stay in good health. Beyond that, the CA reinforces that health – and in particular the capability for health – should not be neglected in policy-making, but should constitute a key component within respective policies. It highlights where policy representatives should provide burdens of proof for certain actions, among them why Germany followed a different policy approach (stimulating its economy) as it itself imposed – via the Troika – on other countries (which had to adopt austerity measures, as for instance Greece). The CA moreover shows that the success of policies should not only be considered within terms of overall life expectancy, incidence and mortality rates, but rather the distribution thereof within societies. Measures should involve other information about the well-being of human beings, both on overall population level, as well as taking into account the individual level, thus stressing the need to strengthen social safety nets.

Jahr's account adds a Kantian perspective that sees persons as an end in themselves and not as a means, reminding not to use people for the benefit of others. While 'first do no harm' focuses on a minimalist morality, Jahr's Bioethical Imperative points more towards the positive value of creating benefits and the conditions for dignity, self-respect and respect for others. Specific

actions according to Jahr's Imperative are identified for increasing public health during scarcity, such as

- supporting economically weak by strengthening social safety nets (in accordance with Keynesian ideology),
- strengthening advocacy towards health needs, e.g. by media coverage,
- increasing health literacy so as to avoid unhealthy habits,
- ensuring vital needs in line with equality of opportunity, e.g. through access to health care,
- actively engaging in health-promoting policies in line with principles of beneficence.

Challenges of scarcity for pharmaceutical innovation and research

Secondly, I addressed the ethical challenges of scarce resources in the context of pharmaceutical innovation and research – specifically the context of personalised medicine and genomics –, presenting an example of how highly innovative and costly medicine is affected by scarce resources in ethical terms.

Under what conditions are new investments in innovative therapies such as personalised medicine justifiable in view of scarce resources? The CA answers this question with the need for investing in treatments that might be necessary for survival. Taking into account the importance of individual and societal freedoms or opportunities, and especially the so-called 'conversion factor', the CA specifies that only individuals with corresponding genetic biomarkers are able to achieve a 'real benefit' from personalised treatments. In terms of scarcity of resources, it can thus be regarded as efficient to only offer treatment to those who can benefit and thus attain better health from personalised medicine, and to reduce the expenses of futile treatments for persons who do not possess matching genetic biomarkers. Social arrangements can help to promote research and development of personalised medicines and introducing reimbursement schemes with the goal to enable access to those therapies for those who can achieve 'real options' to benefit from personalised medicine. This can reduce opportunity costs in an environment of scarce resources, while efficiency, equity and access can be safeguarded.

In research, ethical conduct also is anew in the spotlight due to increased competition arising from scarce resources and limited funding opportunities. A network of responsibilities was established as a heuristic framework through which changes and complexities in research ethics are modelled and can be systematically conceived. It takes into account the broader social dimension of research by identifying six other main

stakeholders besides the researcher, which are: research subjects, colleagues, editors/publishers, professional associations, society at large and – especially relevant in times of economic crisis and austerity – universities and funders. Integrity of research is challenged on diverse levels, and can be addressed by applying the network of responsibilities. Focusing on research ethics and integrity on diverse levels and taking into account all stakeholders can make research better, more truthful and thereby more socially acceptable, which is important since it influences support for research in general, which in times of scarcity is often reduced. By promoting accountability and public trust through such network of mutual responsibilities and rights, emphasis on moral values can be regarded as a driver for science, especially in times of increased competition.

Perceptions of European policy-makers: a qualitative reality check

Finally, an explorative interview study assessed how European policy-makers perceived the economic crisis with regard to health and ethics in decision-making. All interviewees recalled difficult and strenuous situations where they had to prioritize between distinct areas to focus on and invest in, for example around choices between medications, health professional staffing, care specific equipment, or urgent infrastructure issues. Values were identified which they deemed as important within the policy-making process, such as trust and responsibility. Policy-makers furthermore reported about possible health policy measures in response to the crisis, which they think could improve the overall health situation of EU citizens. Among them are the prioritisation of vulnerable groups, enforcing empowerment and health literacy as an instrument for saving costs, not cutting preventive care and spending more on health while reducing spending in other sectors, e.g. defence. They explicitly expressed the need for ethical tools and assistance in terms of policy advice for reaching morally sustainable decisions in health policy matters. The study shows that ethical concepts and values frequently come into play in health policy-making, and that ethics is highly relevant in policy-makers' daily decision-taking.

The thesis carved out conditions and values that can provide policy-making with a better ethical basis. Values play a central role in morally guiding action and shift away from hard economic measures and criteria. It became apparent that is crucial to not only look at overall population health during times of austerity and crisis, but at every single individual, given that every person has an absolute worth – as pronounced by the CA. Generally, little attention is given to ethics as such during those debates on public health. The thesis

contributed to what is ethically at stake for health during austerity.

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WHY WE EDITED

“Ethical, Legal, and Social Aspects of Healthcare for Migrants: Perspectives from the UK and Germany”

Kuehlmeyer K, Klingler C, Huxtable R (Eds.) (2018). *Ethical, Legal and Social Aspects of Healthcare for Migrants: Perspectives from the UK and Germany*. Abingdon and New York: Routledge. ISBN 9781138056541 - CAT# Y328966.

The book builds on an interdisciplinary, international workshop for early career researchers that we conducted in 2016 in Munich. The workshop and book were kindly funded by the German Ministry of Education and Research (2015-2018).

Background

It all started with an elective seminar for medical students in their first two years of medical school at LMU Munich. Corinna Klingler and Katja Kuehlmeyer conducted such seminars for some years which focused on the ethical issues arising from healthcare provision in a globalized world. As part of this seminar, we routinely organized a field trip, for example, visiting open.med Munich, a volunteer-based walk-in clinic for patients without health insurance, which also offers care

for undocumented migrants. Our seminar discussions sensitized us to ethical challenges in the healthcare provision for migrants and the idea for the workshop arose from our desire to get a broader overview, challenge arguments and formulate or justify solutions. By 2015, the issue appeared to be both highly topical and very important. Our idea (and application for funding) preceded the sudden, rising influx of refugees entering European countries around this time, such as those fleeing war and conflicts, particularly from countries such as Syria and Iraq (Bundesamt für Migration und Flüchtlinge 2016). We were surprised – indeed, shocked – by the fast-changing narratives in the political discourse and the consequent legal changes made in various European countries to the detriment of migrant health. We were certainly not prepared for the increase of public discrimination against migrants, especially refugees and asylum seekers. While these developments did not initiate our interest in the topic, they motivated us in advancing our work.

In planning the workshop, we considered a comparative perspective valuable, since different countries have implemented significantly different regulatory regimes (fortunately, this was also required by the funding scheme). Accordingly, we approached Richard Huxtable with the idea to compare how the UK and Germany approach pending challenges in the healthcare for migrants, and he enthusiastically joined the team. We also garnered support from Hella von Unger and Georg Marckmann with the idea of initiating a collaboration between the Institute of Sociology (where Hella von Unger is based) and the Institute of Ethics, History and Theory of Medicine of LMU Munich (where Georg Marckmann, Corinna and Katja are/were based). They were both interested in the issues at hand as well as in fostering a collaboration between the two institutes and in bringing together the different disciplinary perspectives. At that time, Hella von Unger was working on a DFG-funded project on changing categories in discourses on prevention of infectious diseases, which reflected on how categories relating to migration were construed and used in health research. We were happy to learn from that project during the workshop. This collaboration also brought Dennis Odukoya to the organising team, a social scientist (anthropologist), who was a research associate in Hella von Unger’s project team. Hella von Unger invited Oliver Razum to complete our team, whose outstanding expertise and experience with research on the health of migrants was highly welcome.

The Workshop

Building on our shared interest, we sought to expand our knowledge and exchange perspectives on different challenges in the healthcare for migrants and to give early career researchers the opportunity to participate

actively in this endeavour during a one-week-workshop in Munich, Germany. We also envisaged the project as providing an opportunity to increase and enhance the bioethical scholarship on migration and health. The social sciences have long contributed to the field of migration research, but bioethical work has been rarer and has tended to focus primarily on a specific question in the context of healthcare provision for migrants (e.g. granting access to health care or making end-of-life decisions for patients of Muslim background). A publication could, however, bring together the various perspectives.

Seeking to cover and integrate a range of topics and perspectives, our workshop sought to address the following themes: (1) categorizations and terminology used in migrant health (research); (2) questions of (in-)justice with relation to access to healthcare; (3) questions surrounding responsibility for overcoming barriers in healthcare provision for migrants; and (4) culture-sensitive care and intercultural sensitive healthcare institutions. Our call for abstracts received brilliant responses, resulting in the workshop comprising 15 contributors from the UK and Germany, plus a researcher from Canada. For those interested in the topics discussed during the workshop, we suggest reading the excellent conference report written by two participants, Nora Gottlieb and Peter West-Oram (West-Oram & Gottlieb 2017).

The Volume

The workshop participants were invited to submit their work to a peer-reviewed special issue in *Bioethics* or to an edited volume or to both. For the special issue (*Bioethics* 2018; 32(6)), we also released a call for papers, resulting in a collection of five articles plus an open access editorial (Klingler, Odukoya & Kuehlmeier 2018). The special issue focused on two topics: reasons and strategies for increasing access to healthcare for migrants and the accommodation of diverse (presumably culturally formed) needs, beliefs, and preferences in healthcare provision for migrants.

Meanwhile, Routledge kindly accepted the proposal for an edited volume based on the diverse workshop themes. Unfortunately, as sometimes happens in these endeavours, almost half of the initial authors and one of our editors were unable ultimately to contribute as planned. Fortunately, we were able to recruit expert contributors, who further enriched the debates included in the book.

Beyond some of the organisational challenges, there were also substantive questions to address, such as the matter of distinguishing migrants from non-migrants and how best to discuss health issues that are migrant-specific. On the one hand, there is the problem that

introducing distinctions can foster discrimination e.g. if research shows that migrants from country X have a higher burden of disease Y, this might be used to depict this group as a threat. But, on the other hand, making such distinctions might be necessary for detecting – and, ideally, then overcoming – the particular challenges that migrants face. There is also the issue of vulnerability, such as the vulnerability that is caused by the circumstances in which migrants might be forced to live. But, having judged a person to be in a vulnerable condition, what conclusions should then be drawn? Our contributors offered different understandings of this issue, from which we learnt a great deal.

Indeed, we learnt – and hope readers will learn – much from the various perspectives on these and other topics. Our research associate, Simon Böhm, who worked hard on preparing the formatting of the chapters and references of the book, offers a short summary of the content of the book in Box 1. We are very grateful to him for his help then and now.

Box 1: Short summary

The book consists of 16 chapters by all-in-all 28 contributors addressing migrants' health and their need for public healthcare. The term 'migrant' is understood in its broadest sense. Hence, a variety of different migration constellations are discussed. The book focuses on healthcare for migrants in Germany and the UK. Both can be considered immigration countries. The volume is divided in four main sections, starting with a focus on **migrants' health in Germany and the UK**. The book begins by offering an overview on migrants' current health situation in both countries, with the help of data from public health surveillance and research. Section II shifts the focus to **migrants' access to healthcare**, especially regarding aspects of international legislation. In section III, it gets self-reflective: Our authors discuss schemata and thinking paradigms that together construct **the concept of a 'migrant'** and, as such, has an impact on how research about this group is conducted. Our last section is devoted to practical approaches on how to navigate pluralism in healthcare. Summing up, this volume is a collection that offers reflections and answers to pending questions in the health care provision for migrants in the UK and Germany.

Simon Böhm, Research Associate, Institute of Ethics, History and Theory of Medicine, LMU Munich, Germany

In recent months, the media seems quieter about the struggles of migrants than had been the case when we started working towards the workshop and follow-up

publications. But, today, people are still fleeing their countries for various reasons, among them war, political, racial or religious discrimination, hunger and maybe even due to dwindling hope that life will improve. We hope, wherever they are, that they will be received in a spirit of solidarity and respect and that their health needs will be met. We also hope that our edited volume is not the end of deliberation in this area, but will help to continue and expand the discourse on migrant health in medical and public health ethics (and perhaps beyond). We, finally, hope readers will enjoy the different contributions as well as our suggestions for how we might frame the issues surrounding adequate healthcare provision for (and by) migrants.

Katja Kuehlmeyer (Munich), Corinna Klingler (Berlin) and Richard Huxtable (Bristol)

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BOOK REVIEW

Climate Youth Lutter contre l'inertie face au dérèglement climatique – Les jeunes s'engagent

« Les mobilisations qui essaient en Suisse et ailleurs en Europe frappent par leur ampleur, leur jeunesse et leur ton radical », selon un observateur. Les Marches pour le climat du 2 février 2019 dans les villes de Suisse ont rassemblé plus de 40'000 participants. Parmi les injonctions lancées sur des centaines de pancartes et autres bannières : « Les dinosaures aussi pensaient qu'on avait le temps », « La planète, tu la préfères bleue ou cuite ? », « Il n'y a pas de planète B ». Plus politique : « Sauver la banquise plutôt que les banques » (on sait que la glace des deux pôles fond à grande vitesse). Et de nombreuses expressions déplorant que les politiques dorment.

L'engagement des jeunes s'est concrétisé récemment par les Semaines de la durabilité organisées par des groupes d'étudiants, au début mars, dans plus de vingt Hautes Ecoles de Suisse (Sustainability Week

Switzerland, SWS –www.sustainabilityweek.ch). La multiplicité et la variété de ce qui a été mis sur pied impressionne. Selon le site de SWS : « Nous croyons que les Hautes Ecoles veulent mettre en place des campus durables (*sustainable*) mais elles peinent à y arriver (...) Notre vision est d'intégrer la durabilité dans tous les aspects de la vie de nos institutions et les aider à devenir des 'role models' pour la société en général. L'impact potentiel au niveau global est énorme. »

A Lausanne, c'est sur le thème « Changer le système, pas le climat » qu'a eu lieu le lancement de cette Semaine, par le Prix Nobel Jacques Dubochet. Il est convaincu que la dynamique a changé de camp et souligne : « Nous avons impérativement besoin de l'aide des jeunes pour sortir du carbone dans 20 ans, en tout cas en 2050 ». A été évoquée Greta Thunberg qui est allée au WEF de Davos dire que « la seule chose sensée est de tirer le frein de secours. » En stigmatisant l'incurie climatique actuelle, le philosophe Dominique Bourg, figure des débats dans le monde francophone, a rappelé les multiples indicateurs pointant la « Grande accélération » du dernier siècle (1). Il a répondu aux « révalo-climato-sceptiques » et à leurs critiques bruyantes des mesures drastiques nécessaires - correspondant à des changements majeurs de nos modes de vie (voir 2) : « Non, il ne s'agit en rien d'écofascisme, mais des moyens de préserver l'habitabilité de la Terre ». Il faut absolument éviter d'aller au-delà de 2 degrés de réchauffement, au risque sinon d'évolutions irréversibles. Exemples : les Hautes Ecoles s'emploient activement à limiter les vols en avion de leurs collaborateurs (qui aurait osé y penser il y a quelques années ?). Le canton de Genève a décidé que les voyages scolaires ne peuvent plus utiliser ce moyen...

Puis, le 15 mars, les « Grèves pour le climat » dans des centaines d'endroits du monde ont connu un succès impressionnant (60'00 personnes rien qu'en Suisse, pour 8 millions d'habitants). Mais il faut bien s'attendre aux réactions de ceux qui rêvent encore à une croissance sans limites et ne veulent aucune restriction à leur liberté.

Élément rarement évoqué : c'est que nous avons peur, écrit (en relevant que les politiques ne sont pas à la hauteur des enjeux) un pasteur chargé d'une rubrique éthique dans un journal politique du canton de Vaud. Jean-François Ramelet : « L'émergence d'une intelligence collective est indispensable. Cela ne se fera pas sans la reconnaissance que nous sommes tous peu ou prou habités par la peur et le sentiment d'impuissance devant l'ampleur des problèmes que les scientifiques sont unanimes à décrire. La peur transpire des sarcasmes et des discrédits que suscitent les manifestations pour le climat. Cette peur doit devenir le moteur de la prise de conscience et de la mobilisation. » (3). Dans un contexte où devraient prédominer la

science et les faits avérés, on sait cependant que les croyances ont une large place ; entre autres chez ceux qui ne veulent pas voir ni écouter ou qui, comme certains aux Etats-Unis, disent « Si Dieu a mis chez nous des gisements de charbon, c'est bien pour qu'on en profite »... L'émotion principale qui nous inhibe serait-elle la peur de l'inconnu ?

1. <http://www.igbp.net/globalchange/greatacceleration.4.1b8ae20512db692f2a680001630.html>
2. Daniel W. O'Neill, et al. A good life for all within planetary boundaries. *Nature Sustainability*, vol. 1, February 2018, 88-95.
3. J.-F. Ramelet. Question de valeur. *Tribune (Lausanne)*, No2/2019, p. 14.

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BOOK REVIEW

Ethical, Legal, and Social Aspects of Health Care for Migrants – Perspectives from the UK and Germany

Katja Kuehlmeier, Corinna Klingler, Richard Huxtable (eds.) (Routledge, 2019), ISBN: 978-1-138-05654-1/978-1-315-16524-0, 290pp.

The migration flow into Europe during the last decades has led to ethnically diverse populations in European countries. Both theorists and practitioners have the duty to examine the subject of health care of migrants from various perspectives corresponding to the disciplines they minister. In this context, Katja Kuehlmeier's, Corinna Klingler's, and Richard Huxtable's terrific collection, *Ethical, Legal, and Social Aspects of Health Care for Migrants – Perspectives from the UK and Germany* offers a state-of-the-art, multidisciplinary overview of migrants' health care in the UK and Germany, countries with a long history of immigration. Before I move on to reviewing the book, I think it is necessary, at this point, to mention that I am working at the Centre for Ethics in Medicine, of which director is the Professor of Medical Ethics and Law Richard Huxtable, one of the three editors of the collection. However, this has not obstructed me from doing my duty as a reviewer, namely to approach this piece of work with an objective mind.

The book begins with the foreword, the preface, and the introduction, in which editors pose three main questions: (1) how to conduct migrant -and migration – sensitive health surveillance and research, (2) how to regulate migrants' access to and uptake of health care, and (3) how to ensure culturally sensitive health care provision, which appropriately seeks to navigate

pluralism. The tome then is divided into four Parts, which almost (but not exactly) map onto the three main questions from the Introduction. Part I titled 'Migrants' health in Germany and the UK' is divided into four chapters focused on the health of migrants and ethnic minorities in both countries. Part II titled 'Migrants' access to health care' consists of four chapters focused on the rights and entitlements of migrants both at international, regional (EU), and domestic (UK, Germany) level. Part III titled '(Re)constructing migrants in health research' is divided into three chapters focused on questions concerning public health and the social categorisation of migrants, ethnic groups, and locals. Finally, Part IV titled 'Navigating pluralism in health care' consists of the last five chapters of the book, which are focused on social pluralism in relation to five specific health care issues: (1) the psychological counselling and psychotherapy of refugees, (2) the female genital alteration, (3) the overseas-trained doctors, (4) the migrant physicians, and (5) the end-of-life decision-making for children with life-limiting illness. The book concludes with three short Commentaries focused on: palliative medicine, bioethics, and clinical ethics.

More specifically, in the general introduction of the book, the editors start with defining the term 'migrant' and addressing the reasons of migration across borders, as well as the three main areas covered by the collection, namely the migrants' health, their need for and uptake of public health care, and their health care entitlements. Following the general introduction, chapter 1, written by Oliver Razum and Judith Wenner, explores the health of migrants and ethnic minorities in Germany. The authors stress the risks and barriers faced by both *migrants* who seek protection and asylum (refugees), and *immigrants* whose aim is to improve their economic and social condition. In chapter 2, titled 'The health of migrants in the UK: Evidence and implications for health care', the author, Hiranthi Jayaweera, aptly points out the fact that it is not only the migration that affects health, but also the health of migrants that affects their lives in the host country, e.g. their employability participation. Chapter 3, titled 'Bearing witness: Observations of the health of people without access to the regular health care system in Medicines du Monde's (MdM) health care and advocacy programmes in London and Munich', is written by Lucy Jones, Anna Miller, Sabine Furst, Carolin Bader, and Lea Gelfert. The authors focus on the health of migrants excluded from public health care services in Germany and the UK. In the last chapter of the first part of the book, titled 'Dynamics of informal exclusion: Migrants' health as experienced in the City Lab Bochum', Christiane Falge focuses on the City Lab Bochum, a long-term collaborative promotion project, established to provide space where university and urban players

can meet at eye level in order to grasp the complexity of 'actual people's lives as lived'.⁵

Part II of the collection starts with Amrei Muller's chapter titled 'Migrants' right to health in international and European human rights law'. Muller insightfully stresses and discusses two tensions: first the tension between human rights, including migrants' human right to health, and citizens' rights, and, second, the interaction between international and domestic human rights law –both seen as 'fruitful' tensions in the sense that they gradually increase the rights of migrants, including their right to health care, in the host countries. The following chapter (chapter 6) titled 'Entitlements to social health benefits for asylum seekers and refugees in Germany' is written by Markus Kaltenborn. The author focuses on the medical care for foreigners in Germany. Within this context, several important issues are discussed; for instance, the responsibility for the costs of medical treatment in cases such as organ transplants. In chapter 7 titled 'Access and entitlements for migrants and visitors to the UK in the English National Health Service', the authors Sarah Steele and Cormac Devlin examine the admittedly complex system for charging and exemptions for National Health Service (NHS), that is, England's state health provider. In chapter 8, titled 'The right to health for all? Debates surrounding access to health care for asylum seekers in Germany', Sabine Klotz focuses on the access to health care in Germany. The German regulation, as Klotz states, implies limited access to health care for asylum seekers focused on medical treatment for acute diseases and to those in pain.

Part III of the collection starts with Penelope Scott's and Hella von Unger's article titled 'Questioning categorisation practices: "Migrants" and "ethnic groups" in public health classification(s)'. Authors focus on the classifications involving categorised groups and populations according to their ethnic background or migration status. In chapter 10 titled 'Culturally sensitive palliative care and research: What should we do with "those people", or what should we do with ourselves?', Piret Paal focuses on palliative care, namely the treatment of people aiming at relieving their physical, psychological, social, and spiritual sorrows. In the following chapter (chapter 11), titled 'Using superdiversity as a lens to view migrant health: Reflections on ethical and practical implications of an exploratory study involving community researchers', the author, Antje Lindermeyer, presents and discusses the results of an exploratory study into the health histories of recent migrants to the UK guided by the notion of

superdiversity. The author focuses on the ethical considerations arising before and during the research.

Finally, Part IV begins with Kerstin Hein's and Barbara Abdallah-Steinkopff's essay titled 'Challenges in the provision of mental health care for refugees in Germany: A socially and culturally sensitive approach to psychological counselling and psychotherapy'. In this essay, the authors discuss the mental health of refugees and asylum seekers. In chapter 13 of the book, titled 'Female genital alteration in the UK: A failure of pluralism and intersectionality', Arianne Shahvisi focuses on legislation around FGA in the UK. Specifically, Shahvisi examines the responses to female genital alteration (FGA) of *adult* women within the country. In the following chapter (chapter 14), titled 'Integration, identity and elite migrants: Capturing the perspectives of overseas-trained South Asian doctors in the UK', Yasmin Ghazala Farooq studies the highly skilled or so called 'elite' migrants, specifically overseas-trained South Asian doctors who practised as general practitioners (GPs) in the UK. In chapter 15, titled 'How to support migrant physicians in navigating through an unfamiliar health care system: Findings from a qualitative interview study', Corinna Klingler and Georg Marckmann have focused on the need to implement comprehensive support structures to improve professional integration of migrant physicians. Finally, in chapter 16, titled 'Migrants, pluralism and end-of-life decision-making for children with life-limiting illness: Perspectives on the case of Josip', Katja Kuehlmeier and Monika Fuhrer focus on a specific case, in order to highlight the challenges arising when a decision must be made about life-sustaining treatment by families which are in a foreign environment with a foreign care system and language. The description of the case is followed by three independent commentaries, which reflect on its ethical, legal, and social implications.

Definitely, the *Ethical, Legal, and Social Aspects of Health Care for Migrants* is a logically-structured collection, with an excellent introduction, and narrative of individual chapters, which fit together well as parts of a whole which gives meaning to its parts, and vice versa. In terms of content, the collection perfectly responds to the initial difficult questions posed by the editors, namely: (1) how to conduct migrant -and migration – sensitive health surveillance and research, (2) how to regulate migrants' access to and uptake of health care, and (3) how to ensure culturally sensitive health care provision, which appropriately seeks to navigate pluralism. The book admittedly enriches our knowledge and understanding of ethical, legal, and

⁵ Niewohner, J. (2014). Ökologien der Stadt: Zur Ethnographie bio-und geopolitischer Praxis. *Zeitschrift furr Volkskunde*. 110(2): 205

social aspects of health care for migrants, stimulating further discussion between advocates, researchers, and policy makers. Eventually, this collaborative endeavour of theorists and practitioners from various disciplines: healthcare, law, ethics, politics, anthropology, and social science renders the subject of healthcare of migrants a multidisciplinary subject that we all have the duty to examine from all its perspectives.

There is, however, one respect in which this already excellent collection could have been even stronger. Despite the far-reaching questions and intriguing examples of the contributors in the fields of *law* and *social* science and policy, the *ethical* part of the book is less developed. An essay could have been devoted to the ethical aspect of health care for migrants, in general. Another essay could have been devoted specifically to the nature and justification of migrants' right to health care. These additions, I think, would have made the collection even stronger. Yet, we all know that it is very difficult a comprehensive collection of essays to make everyone maximally happy. Setting my small quibble aside, the book is a genuine achievement and a reference point for the current and future situation of migrants with reference to their health care in the European countries.

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BOOK REVIEW

Jean Fonjallaz et Jacques Gasser

Le juge et le psychiatre - Une tension nécessaire

Médecine et Hygiène, Chêne-Bourg/Genève, et Stämpfli Editions SA, Berne, 2017, 223 pages.

Jean Fonjallaz est juge au Tribunal fédéral suisse. Jacques Gasser est professeur de psychiatrie à la Faculté de médecine de Lausanne. Ils publient un livre susceptible de répondre à des manques persistants dans la formation des professionnels impliqués, du domaine médical, y compris au plan éthique, et du domaine juridique. Ceci sur les conditions et impératifs de leurs rôles respectifs en matière pénale, notamment quand des questions se posent sur la responsabilité des prévenus. « Les représentants du ministère public et les parties jouent sur un terrain qui n'est pas celui de l'expert, qui lui procède à un travail fondé sur la connaissance et la réflexion médico-scientifiques. » Ils répondent aussi, dans la foulée, aux souhaits d'information du public intéressé. Ouvrage clair, bien

structuré, couvrant largement le champ en apportant une foule d'informations utiles.

La partie intitulée « Le procès pénal » décrit les sources du droit, les acteurs du procès et son déroulement, les sanctions et les mesures. Les mesures sont envisagées « si une peine seule ne peut écarter le danger d'autres infractions » ; elles visent deux types de personnes : celles qui ont besoin d'un traitement et celles qu'il se justifie de priver de leur liberté car elles représentent un danger trop grand pour la société (notion d'internement).

Un rappel : « Les plus anciennes législations considéraient la folie comme un motif d'exemption de punition (...) On estimait que l'on ne pouvait pas imputer une faute à quelqu'un dont l'esprit est aliéné et il en allait de même pour l'enfant, l'animal ou la tuile qui tombe d'un toit. » Les choses ont changé et les questions de responsabilité (entière, restreinte ou nulle) se sont complexifiées, avec la diversification des codes pénaux. Evolution influencée aussi par l'accent croissant mis sur le respect des droits humains.

Changement de paradigme. « En une quinzaine d'années, la justice pénale est passé d'une logique de punition et de réinsertion sociale à un modèle de gestion du risque mettant au centre la protection de la société. » L'intérêt des milieux professionnels, politiques et médiatiques s'est déplacé de la problématique de la responsabilité à celle du risque de récidive – notion de dangerosité. « Ceci est à la racine des difficultés des experts psychiatres qui doivent se prononcer non seulement sur ce qu'ils savent faire mais également sur des aspects éloignés de leurs préoccupations habituelles - relevant de la sécurité publique. »

Aspects éthiques. En premier lieu, l'expertisé doit être averti que le médecin n'est pas dans son rôle habituel de thérapeute mais qu'il agit sur mandat d'une autorité judiciaire à laquelle il devra communiquer tous les éléments nécessaires - et qu'il n'est donc pas soumis au secret médical dans cette fonction. « Le travail d'expert ne devrait jamais être un travail solitaire. Dans l'expertise à deux, il y a lieu d'adopter une méthode qui valorise le consensus. Ceci permet de travailler les éventuels désaccords et de les expliciter. » La discussion est la partie la plus importante de l'expertise, elle représente l'interface entre le monde médical et le monde juridique. C'est là qu'il s'agit de chercher s'il existe un lien de causalité entre les éléments cliniques observés et les actes reprochés à l'expertisé.

Considérations de fond. « Le droit pénal est fondé sur la conception que chacun est en principe libre d'agir. C'est le libre arbitre, la conscience et la volonté sont présumées (...) La psychiatrie elle a observé que le comportement d'un individu est conditionné par

différents éléments liés à son état mental et à son histoire. C'est le déterminisme. » Aussi : « Le droit fonctionne par catégories et concepts distincts, alors que les psychiatres voient leurs observations dans une certaine globalité et un certain continuum. »

Est-ce que comprendre, c'est excuser ? Excellente question posée à la fin du livre : « Trop souvent, le travail de compréhension du comportement d'une personne est interprété comme excusant ce comportement, avec pour effet de réduire la punition. » On confond là deux choses. Comprendre est de l'ordre de la connaissance, c'est l'action qui vise à accéder au sens, à chercher les mécanismes ou déterminants significatifs d'un acte. Sanctionner, en revanche, est une action d'un autre ordre, qui a pour fin d'appliquer la loi que s'est donnée la collectivité.

« Sans psychiatrie, on reviendrait à un cadre légal où ce ne serait plus l'être humain mais bien l'acte pénal qui serait au centre de la réflexion amenant à fixer la sanction. Il serait alors difficile d'échapper à la règle du 'tarif' pénal, qui ne serait sans doute pas conforme aux aspirations d'une société fondée sur le respect des droits humains. »

Cet ouvrage illustre que le dialogue entre un juge et un psychiatre est susceptible de déboucher sur un résultat concret et utile, aux confins de deux matières dont l'interaction devrait servir le vivre ensemble.

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