

EACME Newsletter

European Association of Centres of Medical Ethics

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EDITORIAL

Dear EACME colleagues and friends,

Recent media coverage of biomedical engineers who have designed a synthetic yeast genome, resequencing the yeast DNA in the process to eliminate redundancy and reduce its size,⁽¹⁾ has briefly brought to public attention a gamut of issues about the preparedness of scientific regulators for the pace of scientific advances. Such concerns are familiar to medical ethics, but any disquiet about the appropriateness of altering the DNA of living organisms for purely cosmetic reasons may well be submerged by apparently more pressing anxieties. Europe is in the midst of bruising political upheavals that bring their own challenges. These are of course close to my mind as a U.K. scholar, since on the day I write this editorial BREXIT has been formally applied for by the British government. As scholars and clinicians within EACME we naturally see both the scientific and the political as within our ambit. The potential costs to human health of economic and civil upheaval are enormous; the great toll that austerity has imposed (and continues to impose) on the health of the people of Europe is already well established. One might well ask *who should* be concerned if such things are not the concern of bioethicists.

With so much to worry about it would seem our work is cut out for us. While, here in at the Centre for Ethics in Medicine in Bristol, we have no plans for EAC-XIT, it is nevertheless heartening to include in this newsletter reports from two new members of our network in this issue; the Institute for Ethics and History of Medicine at the University Medicine Greifswald and the School of Bioethics at Pontificio Ateneo Regina Apostolorum. It would be grandiose to suggest our expanding network

¹ S.M. Richardson et al. Design of a synthetic yeast genome
Science 10 Mar 2017: 1040-1044

is anything more than a glimmer of hope in what can sometimes appear to be dark times. Yet spaces such as EACME, where individuals with diverse national, professional and personal backgrounds can exchange ideas in a spirit of openness and collegiality are important in times like these. I am hopeful, then, that such small signs mean we shall continue to build bridges, rather than burn them.

Giles Birchley, Editor

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INTERNATIONAL CONFERENCE FOR YOUNG SCHOLARS 15 – 19 FEBRUARY 2016 IN BOCHUM GERMANY

“Beneficial coercion in medicine? Foundations, areas of conflict, prevention”

“Ethical and legal frameworks for coercion in clinical psychiatry: creating international awareness by presenting a conference volume”

This contribution deals with the realization of a conference volume to a conference for young scholars on coercion in psychiatry.

The use of coercive measures in clinical psychiatry is an ongoing topic of debate in several European countries. This debate centres around the controversies between the potential and intended benefits of coercion versus the negative consequences as possible physical and psychological harm. Differences between countries are visible in both the political and ethical stances on the use of coercion in clinical practice and in the type of coercion used most frequently.

Changing perspective

An example for a change in perspective concerning the use of coercive measures has been the situation in the Netherlands. For a long time the use of coercive medication, being an intrusion of bodily integrity, was viewed as the most restrictive intervention. As a consequence however, the number and duration of seclusions as well as the number of aggressive incidents in psychiatric hospitals rose to a level well above other European countries. Changing opinions on the use of coercive measures in the Netherlands led to a still ongoing change in clinical practice, moving from seclusion towards early intervention by drugs. This development is striking when compared to recent developments in Germany, where for a long time the use of involuntary medication was widely accepted and seen as therapy. In 2013, the Central Ethics Committee

of the German Medical Association (ZEKO) published a statement in which coercive medication is viewed as the most invasive measure and coercive measures such as mechanical restraint or seclusion should be preferred over medication, especially in situations in which patients pose an acute danger to others.

This example shows that important differences exist in the use of coercive measures that relate to the attitude towards the use of certain coercive measures. Besides legal factors, ethical aspects play an important role in the current debate. Different ethical perspectives as care ethics and biomedical ethics point to different stances on the use of coercion. Despite these differences, similarities can be seen between legal procedures in both the Netherlands and Germany and the ethical issues addressed in the ongoing debate on the use of coercion. However, insight in the differences and similarities in both the legal and ethical frameworks of European countries is lacking.

Seeking insight and collaboration

With this goal in mind, a conference on “Beneficial coercion in medicine? Foundations, areas of conflict, prevention” was organized by the Institute for Medical Ethics and History of Medicine of the Ruhr University of Bochum. At this five day conference, twelve young scholars from neighbouring European countries discussed the pressing issues mentioned above. The aim of the conference was to provide insights in both ethical and legal frameworks of European countries and to explore differences and similarities between these frameworks. This included an understanding of the factors that contribute to the developments in political stances on the use of coercion, the influence of legal frameworks, quality standards and evaluation. This could increase awareness among young scholars researching coercion in psychiatry.

All young scholars presented their research from both philosophical and practical perspectives on the use of coercion. For example, Tonje Lossius Husum from Norway discussed mental health care staff’s experiences of ethical challenges related to the use of coercion in care, while Eva Kowalinsky from Switzerland examined the possibilities of the overestimated safety of locked doors in psychiatry. Anna Werning, one of the young scholars from Germany, presented her personal experiences on coercion in psychiatry, and discussed if peer support could prevent the use of coercion in psychiatry. Laura van Melle proposed that High & Intensive Care (HIC) in psychiatry is based on the care ethics framework, and that it helps to prevent coercion, and Hannah Edelbroek from the Netherlands presented the ethical dilemmas of coercive measures in an ambulatory setting.

Besides the presentations of the young scholars, some

senior lecturers were invited to deepen the ethical challenges related to coercion in psychiatry. Prof. Dr. Phil. Thomas Schramme presented on the conceptual and ethical aspects of paternalism, and Prof. Dr. Jur. Tanja Henking discussed the philosophical foundations of the German legal framework on the use of coercion in psychiatry. Furthermore, Dr. Rer. Nat. Julia Haberstroh presented her research on the capacity to consent to medical treatment among persons with dementia by means of resource-oriented communication, while Dr. Yolande Voskes provided more insights in the care ethics perspective and on how this framework could guide psychiatric staff in reducing coercive measures. Moreover, Prof. Dr. Phil. Guy Widdershoven gave a public lecture at the Department of Psychiatry, Psychotherapy and Preventive Medicine, LWL University Hospital, Ruhr University Bochum, and presented the advantages of moral case deliberation (MCD) to increase awareness of ethical challenges of coercion in psychiatry. Widdershoven argued that MCD supports moral thinking and can be a practical means to start the necessary dialogue on coercion.

The presentations by both senior lecturers and young scholars were alternated by a workshop by Prof. Dr. Med. Dr. Phil. Jochen Vollmann and Dr. Med. Jakov Gather on clinical ethics consultation in psychiatry. Putting more focus on the search for ethically justified decisions in clinical practice. In addition, the young scholars visited the LWL Forensic Psychiatric Hospital Herne, where they talked to staff members and patients, and saw several psychiatric wards and the isolation room. This visit gave the non-Germans the possibility to see the differences and similarities between forensic psychiatric hospitals in their country and Germany.

Starting a network

The conference provided new insights on coercion in psychiatry and differences and similarities between European countries to all young scholars and senior lecturers. However, all participants agreed that one conference cannot be enough, and that collaboration between researchers and countries is a necessity to reduce coercion in psychiatry. The conference can therefore be seen as a starting point. We will continue the debate through an international network. The first result of which is the jointly composed conference volume: Gather J, Henking T, Nossek A, Vollmann J (eds.) (forthcoming): Beneficial coercion in psychiatry? Foundations and challenges. Münster: mentis.

Our special thanks go to Alexa Nossek, Jakov Gather, Tanja Henking, Jochen Vollmann and to the other staff members of the Institute for Medical Ethics and History of Medicine of the Ruhr University of Bochum for organizing this conference.

Conference organizers:

Institute for Medical Ethics and History of Medicine, Ruhr University Bochum: Dr. med. Jakov Gather, M.A. / Prof. Dr. iur. Tanja Henking / Alexa Nossek, M.A. / Prof Dr. med. Dr. phil. Jochen Vollmann. The conference was funded by the German Federal Ministry of Education and Research (BMBF).

Senior researchers:

Prof. Dr. phil. Guy Widdershoven (Amsterdam) | Prof. Dr. med. Georg Juckel (Bochum) | Prof. Boris Schiffer (Bochum/Herne) | Dr. rer. nat. Julia Haberstroh (Frankfurt a. M.) | Dr. Yolande Voskes (Amsterdam) | Prof. Dr. phil. Thomas Schramme (Liverpool)

Youngscholars:

Mathias Wirth (Hamburg) | Lucy White (Hannover) | Hannah Edelbroek (Amsterdam) | Ramona Geisler (Berlin) | Anna Werning (Bochum) | Tonje Lossius Husum (Oslo) | Laura van Melle (Amsterdam) | Eva Kowalinski (Basel) | Alexander Stingl (Erlangen-Nürnberg) | Gregor Scherzinger (Luzern) | Susanne van den Hooff (Alkmaar)

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EACME PRIZE WINNER 2016 MARCELLO IENCA

Marcello Ienca, M.Sc., M.A., is a PhD candidate and research assistant at the Institute for Biomedical Ethics (IBMB), University of Basel, Switzerland. Prior to that, he studied philosophy, cognitive science and bioethics in Rom, Berlin and Leuven. In 2012/13 he was Barbara-Wengeler Visiting Scholar at New York University. He is the chair of the Student/Postdoc Committee of the International Neuroethics Society (INS) and the current coordinator of the Swiss Network for Neuroscience, Ethics and Law.

His research investigates the ethical and social implications of human-machine interaction, with special focus on neurotechnology, robotics and artificial intelligence. His current projects articulate into two major components:

- I. Ethical design in intelligent assistive technology for people with dementia and age-related cognitive disability
- II. Neurosecurity issues associated with clinical and non-clinical uses of brain-computer interfaces (BCIs)

The main objective of his research is to use ethical analysis to enhance medical engineering for the benefit of patients and general users. In addition, he is concerned with the convergence of neuroethics with the ethics of artificial intelligence with the purpose of

harmonizing ethical reflection and guidance across the entire cognitive continuum.

Intelligent Assistive Technology for Dementia

According to the WHO, dementia is one of the major causes of disability and dependency among older people worldwide. Given the aging of the world population and recent unmet expectations in pharmacological therapy, dementia poses a major problem for global health. Rapid advancements in artificial intelligence, robotics, pervasive and ubiquitous computing - combined with new developments in human-machine interaction - open the prospects of alleviating the global burden of dementia and age-related cognitive disability. However, the clinical implementation of these Intelligent Assistive Technologies (IATs) is still reportedly low due to translational lag, suboptimal information transfer among designers and clinicians and the prevalence of top-down models in product development.

In relation to IATs, Ienca has advocated three normative positions. First, he has argued that there is an urgent need to monitor the evolving spectrum of IATs for dementia and assess the clinical validity, effectiveness, usability, applicability and safety of these technologies. Second, he has argued that designers and developers have a moral obligation to shift from top-down to patient-centered and participatory approaches to technology design. Such approaches should proactively investigate the needs and wishes of elderly adults with dementia and iteratively adapt product designs to such needs and wishes. Third, given the vulnerability of elderly adults with dementia and the complexity of the human-machine interaction enabled by IATs, researchers have a moral obligation to proactively incorporate ethical considerations at the level of product design. This will require a shift from reactive models of ethical evaluation (based on the post-development assessment of finished products) to a “proactive ethics of technology” where ethicists and engineers collaboratively attempt to embed ethics into the technology design through user-centered and value-sensitive dynamics.

To address the first challenge, Ienca and his senior colleagues at IBM (Prof. Bernice Elger, Dr. Fabrice Jotterand and Dr. Tenzin Wangmo) - jointly with Prof. Reto W. Kressig, chair of Geriatrics at Basel University Hospital, Dr. Maurizio Caon from the Humantech Institute and Alessandro Scoccia Pappagallo from Fooder Ltd - have created a systematic technology index of IATs for dementia and age-related disability. This index reveals that the IAT spectrum is expanding rapidly in volume and variety

over time (to date, there are over 590 IATs with direct application to dementia care with the total number of devices doubling every five years), and encompasses intelligent systems designed to support various assistive tasks and clinical uses. At the same time, their results indicate the persistence of structural limitations to successful adoption including partial lack of clinical validation, insufficient focus on patients' needs and absence of ethical considerations.

To accelerate the transition to patient-centered and participatory approaches to technology design, IBM researchers have developed a normative framework for user-centered and value-sensitive design in assistive technology for neurocognitive disability. In addition, they have proposed ethical guidelines for research and clinical practice aimed at protecting users and maximizing the benefit of IAT in assisting older patient with special focus on socially assistive robotics. Their recommendations focus primarily on informed consent, privacy, data security, safety, autonomy, and equality. At the level of informed consent, they have argued that the combination of advance directives, behavioral observation and confirmation by proxy may offer a triple protection for the residential use of intrusive IATs among people with dementia. In relation to privacy, they have recommended that the collection and usage of behavioral and physiological information from elderly people with dementia should meet the conditions of transparency, legitimate purpose and proportionality. In addition, they have argued that end-users should be empowered during both the development and the implementation process while IATs should be designed to promote their decisional and executional autonomy. Finally, they have warned that a profit-oriented market of IATs could make the benefits of IATs accessible only to affluent individuals, hence exacerbate preexisting socioeconomic inequalities. Therefore, justice-oriented soft regulations should prevent this risk through coordinated strategies such as incentives for low-cost devices, the dissemination of open-source initiatives such as the OpenBionics and the development of welfare strategies to guarantee fair and even access to technology for everyone.

Neurosecurity

The pervasive and ubiquitous distribution of neurodevices in both clinical and non-clinical settings poses the additional ethical challenge of protecting the privacy and security of neural data. Research has shown that neurotechnologies such as brain-computer interfaces (BCIs) and the combination of neuroimaging/neurorecording techniques and machine learning algorithms can be used to extract sensitive information from a person's brain (e.g. preferences or personally identifiable information) without their

authorization or consent. To address at the normative level this emerging problem, Ienca and Prof. Pim Haselager from the Donders Institute for Brain Cognition and Behaviour at Radboud University have investigated the ethical implications of what they call "malicious brain-hacking", i.e. the unauthorized and malevolent access to or manipulation of neural information from neurotechnology users. In this study, they provided an overview of the possible vulnerability sources of BCIs and delineated the ethical landscape of malicious brain-hacking. Their analysis focused on four major ethical categories: consent, privacy, agency and personhood. In malicious brain-hacking informed consent is overridden as information is extracted from users without their authorization or consent. This risk does not apply exclusively to criminally-motivated malevolent agents using "brain malwares" such as those based on subliminal stimulation but also to direct-to-consumer companies that replace informed consent for mobile medical devices with the mere acceptance of the product's terms and conditions. In addition, the possibility of extracting private and sensitive information from BCI users represents a significant threat to their privacy and data protection. The magnitude of this risk will increase proportionally to the ongoing increase in processing speed, accuracy and reliability of neurodevices. Finally, the intrusion of malevolent third parties into the BCI cycle as well as the incorporation of artificial intelligence (e.g. machine learning algorithms) into the system might have consequences on the sense of agency and personal identity of BCI users. Victims of malicious brain-hacking and users of artificially augmented BCIs might experience limitations in the voluntary control of their actions also resulting in psychological distress. With the growing market of pervasive neurotech applications, they have advocated the development of neuroprivacy and neurosecurity safeguards (e.g. encryption technology) for consumer-grade devices and proposed to raise awareness on the protection of neuroinformation among individual users.

Converging the Ethics of Natural and Artificial Intelligence

Natural and artificial intelligence are critical areas of investigation in applied ethics. The former is being extensively scrutinized within the field of neuroethics, the latter within the mutually related areas of machine ethics and ethics of technology. However, holistic approaches that provide ethical assessment of the entire brain-machine continuum appear very rare. As natural and artificial cognizing systems get more and more intricately intertwined, Ienca and their colleagues have called for collaborative and transdisciplinary approaches to ethical evaluation.

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THE POSTGRADUATE BIOETHICS CONFERENCE 2016 REPORT

The PGBC is an annual conference aimed at doctoral researchers in applied ethics broadly conceived and provides an opportunity for postgraduate (PG) students and established academics working in bioethics to come together, share their research, and engage with the work of others and in career development activities. The first conference (held in 2006) was initiated by a group of doctoral researchers, including GM's current supervisor, Dr Jonathan Ives, and was funded by the Wellcome Trust.

On 31st August and 1st September 2016 we held the tenth Postgraduate Bioethics Conference (PGBC) at the Centre for Ethics in Medicine at the University of Bristol, funded by the Wellcome Trust and the Institute of Medical Ethics (IME). The theme for PGBC 2016 was 'Bioethics in Theory; Bioethics in Practice'. On day one we had plenary sessions and workshops led by Dr. Jonathan Ives and Dr Lucy Frith on 'Theories and Methodologies in Empirical Bioethics'; Professor Richard Huxtable and Dr. Zuzana Deans on publishing for early career researchers and Dr. Giles Birchley and Mr. Paul Woodgate from the Wellcome Trust on funding. On day two Professor Jose Miola and Dr. Sheelagh McGuinness kicked off our plenary sessions discussing 'Bioethics and Law', focusing on informed consent and abortion respectively; Professor Richard Huxtable then joined them for a panel session on their Ethical Judgements Project; Dr. Giles Birchley and Dr. Sandhi Dheensa discussed 'Bioethics in Practice' looking at best interests in minimally conscious patients and the UK "Genethics" Forum; Dr Wing May Kong (Chair of the IME) then joined them to discuss

how we can engage healthcare professionals in bioethics.

In the spirit of PGBC, all but three of our delegates were able to present their work across our ten parallel sessions that spanned the two day period. The themes ranged from Ethics & Embryos, Moral Distress, Concepts & Methods in Bioethics to Ethics at the End of Life. We aimed to create a safe and non-threatening environment to allow first time presenters to practice their presenting skills which resulted in an atmosphere of lively debate and enquiry.

Due to our generous funding we were able to award five international travel bursaries (with one international delegate unfortunately withdrawing a day before the conference) of £200 which enabled PG students from the United States, Ireland, Germany and the Netherlands to attend. We also awarded twelve national travel and subsistence bursaries of £100 each to PG students across the United Kingdom. We provided the conference at no cost to delegates, which included accommodation, meals, and a networking dinner. This allowed students who may not have otherwise been able to attend a conference to come and meet with peers and academics.

A best abstract prize was awarded to Arianna Manzini for her abstract titled 'Predictive Genetic Testing For Minors For Psychiatric Conditions', and commendations given to Catherine Hunt for her abstract titled 'UK Law Does Not Allow Prospective Parents to 'Prefer' Disabled Embryos- Should It?' and to Sarah Wietan for her abstract titled 'Changing Selves: Decision-Making During Life-Limiting Illness at the End of Life'.

On day one we held a Three Minute Thesis competition (at the bar!), chaired by Dr. Sheelagh McGuinness and judged by Professor Jose Miola, Professor Richard Huxtable, Dr. Jonathan Ives and Dr. Lucy Frith. Eight delegates competed covering: the influence of bioethics on policy development; moral status of embryos; test cases in law; ethical spaces in critical care; moral distress in medical practice; ethical treatment of adolescents; expertise, mechanisms and values in evidence-based medicine; and legal protection for egg freezing. Daniel Tigard (moral distress) won the competition; Faye Tucker (adolescence) was second; and Virginia Novaes Procopio de Araujo (egg freezing) was third.

The conference closed with a lively session titled 'Ask the Experts' chaired by Professor Richard Huxtable with questions from PG delegates to a panel of academics including Professor José Miola, Dr Sheelagh McGuinness, Dr Wing May Kong and Dr Jonathan Ives. Questions ranged from which of our

experts would consider themselves a 'bioethicist' to how they had become involved in bioethics. We received really positive feedback and delegates found that it was a really good mix of both fun and debate.

In recent years, organisers of the PGBC have formed a Postgraduate Student Committee (PSC) within the IME. The PSC is working hard to continue the success of PGBC, organise smaller events throughout the academic year, foster new relationships between postgraduate bioethics students, and nurture a PG research community. So although the prospect of organizing a conference whilst doing a PhD seemed like a very daunting task, on reflection we both thoroughly enjoyed it. The planning, organizing and emailing actually became a welcome break from reading and writing!

This year's PGBC 2017 is all set to be held at the University of Oxford so to keep up to date with calls for abstracts follow us on:

Twitter @IMEpostgrad

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2017 ANNUAL POSTGRADUATE BIOETHICS CONFERENCE OXFORD, 4-5th SEPTEMBER

Dear UK and International Graduate Students,

This 4-5th September the Ethox Centre (<https://www.ethox.ox.ac.uk/>) invites you to Oxford for the 2017 Postgraduate Bioethics Conference (PGBC) (<http://www.postgradbioethics.com/>). Hosted by Ethox DPhil students, the conference will be held at St Catherine's College, Oxford (<http://www.stcatz.ox.ac.uk/>).

Graduate students at Masters or PhD level are eligible to attend and join PGBC's burgeoning community of bioethics scholars. Delegates will give oral presentations and enjoy key note speeches and workshops, as well as bed and board in Oxford.

The theme of this year's Conference is 'Individuals and Populations'. This theme aims to explore a range of bioethics questions at the individual level, the population level, and intersecting issues. Although traditionally oriented towards the individual, bioethics is starting to recognise the ethical significance of

communities and populations in the context of globalisation, technological advances, and 'big data'. Ethox Centre staff and other bioethicists or academics in related disciplines will deliver keynotes and contribute to delegate discussions. Student delegates will apply to deliver short oral presentations about their work. The theme is broad to accommodate students from diverse disciplinary backgrounds (e.g. law, social science, psychiatry, philosophy, and medicine), working in a number of different areas.

The overarching conference objective is to provide a supportive forum for delegates to meet and discuss their work, taking advantage of peer learning opportunities. Workshops will be held to cover such topics as publishing in academic journals, led by editors of the *Journal of Medical Ethics*, and career development in bioethics.

We are pleased to confirm Professor Michael Parker, Professor of Bioethics and Director of the Ethox Centre as our opening speaker. Dr Mark Sheehan, Oxford Biomedical Research Centre Ethics Fellow, is also confirmed. The conference will be held over two days, before the start of the academic term. Overnight accommodation and all refreshments and meals are provided free of charge. There will also be a free conference dinner at the College on the evening of the 4th which all are encouraged to attend. Travel is not covered but it is hoped some travel bursaries will be available.

PGBC and bioethics at Oxford in 2017

The Ethox Centre, based in the Nuffield Department of Population Health, encounters 'big data' on a daily basis, being now housed in the Oxford Big Data Institute (<https://www.bdi.ox.ac.uk/>). Ethox, The Uehiro Centre for Practical Ethics (Director Prof Julian Savulescu), the Wellcome Unit for History of Medicine (Director Prof Mark Harrison), and the Oxford Neuroscience, Ethics and Society Group (PI Prof Illina Singh) are now partners in the Oxford Wellcome Centre for Ethics, Innovation, Globalisation and Medicine (<https://wellcome.ac.uk/what-we-do/our-work/research-centres-and-institutes>). The Centre is designed to provide a platform for collaboration between researchers in ethics, the humanities, and medical sciences. This makes University of Oxford an exciting place to do bioethics in 2017.

The conference venue

In counterpoint to the 'dreaming spires' of older Oxford colleges, St Catherine's College was founded in 1962, the functionalist architecture courtesy of Danish architect and designer, Arne Jacobsen (also known for designs such as the Egg chair).

In this environment delegates can choose to be stimulated by the traditional or modern faces of the University, taking a walk into the traditional heart or falling back on the newer interpretations offered by the College. In particular the College garden, integrated rather than incidental to the building's design, offers a chance for mindful reflection and a blaze of summer colour and structure come September.

How to Apply

A call for abstracts will be sent out to all current postgraduate student networks. We look forward to welcoming you to Oxford.

For any queries, please contact Ethox hosts, Ruchi Baxi or Kate Sahan, at: postgrad.bioethics@outlook.com

END OF LIFE CARE SYMPOSIUM

Introducing the Council of Europe's "Guide on the decision-making process regarding medical treatment in end-of-life situations"

JOINTLY ORGANIZED BY THE COUNCIL OF EUROPE AND ACIBADEM UNIVERSITY

Istanbul, 25 October 2016

Aims and Scope of the Symposium

The Council of Europe and Acibadem University organized a joint meeting in Istanbul on October 25th, 2016. The aims of this symposium were to introduce the printed Turkish version of the Guide to the allied academic, scientific, public circles, and to create an internationally collaborated scientific platform for discussing end-of-life situations from medical, clinical, bioethical, judicial, legal perspectives on one hand and for having a deeper insight into the issue through recent studies carried out in Turkey mainly based on the [Council of Europe's afore-mentioned Guide](https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?documentId=090000168039e8c5). (<https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?documentId=090000168039e8c5>)

The Guide on the decision-making process regarding medical treatment in end-of-life situations was drawn up by the Committee on Bioethics (DH-BIO) of the Council of Europe in the course of its work on patients' rights and with the intention of facilitating the implementation of the principles enshrined in the Convention on Human Rights and Biomedicine (Oviedo Convention, ETS No. 164, 1997).

The purpose of this guide is to serve as a useful tool for informing the public and training professionals. It is

aimed at health professionals, patients, their families and all those who face problematic decisions with regard to medical treatment in end-of-life situations, and provides help for the development of practices. The guide is also a source of material for any discussion held within our societies on the decision-making process regarding medical treatment in end-of-life situations in that it proposes benchmarks relating both to the practices and the principles that can be applied in this context ([Council of Europe http://www.coe.int/en/web/bioethics/guide-on-the-decision-making-process-regarding-medical-treatment-in-end-of-life-situations](http://www.coe.int/en/web/bioethics/guide-on-the-decision-making-process-regarding-medical-treatment-in-end-of-life-situations))

The Participants

More than one hundred twenty healthcare professionals, jurists, bioethicists, philosophers, sociologists, public health and forensic medicine academics, experts from health and social sciences, intensive care and geriatrics units professionals, nurses, care givers, social workers, under and post graduate students of medicine, nursing, vocational schools took part in the Symposium and contributed to the discussions. Assoc. Prof. Dr. Roberto Andorno, from Zurich School of Law, gave a speech on end of life care from a human dignity and human rights perspective. Mr. Ramon Prieto-Suarez, the representative of the Council of Europe DH-BIO, gave information about the Council of Europe's Guide on the the decision-making process regarding medical treatment in end-of-life situations. Prof. Dr. Ergun Ozsunay, the Turkish delegate of the COE DH-BIO, dealt with end of life decisions from legal perspective, substitute decision-making, continuing powers of attorney, advance directives for incapacity. Prof. Dr. Yesim Isil Ulman explained the ethical perspective of end of life care through a multidisciplinary approach. Assoc. Prof. Dr. Tughan Utku, M.D, PhD, from Istanbul University Anesthesiology and Intensive Care Department, talked about futility in intensive care unit from a medical and philosophical perspective. Dr. Gerald Neitzke, M.D, Ph.D, elucidated ethics consultation in end of live decision making. Dr. Elif Cizmeci presented their study on end of life decisions in the intensive care unit based on opinions of relatives. Prof. Inci User, Ph.D., introduced a qualitative study on end of life from doctors' views and experiences. Year IV students of medicine M. Kanjee, D. Yanik and C. Yildiz presented their research on euthanasia from students' perspective.

Preliminary Remarks

The Symposium served the purpose of introducing the printed [Turkish version](#) of the Council of Europe's "Guide on the decision-making process regarding medical treatment in end-of-life situations" (hereafter "the Guide") to academic, medical and public circles,

and to create a platform for discussing end-of-life situations in Turkey.

(<https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?documentId=09000016806ad65a>)

The Guide generated interest, and was viewed as a valuable source material for societal discussions on the matter. It was recalled that the Guide concentrates on the questions on which a consensus exists among European countries. This is why it does not address or take a position on the most controversial topics such as assisted suicide or euthanasia. These topics were nevertheless also discussed during the Symposium, namely underlining the risks and abuses that could ensue if such practices were legalised.

The Symposium also permitted gaining a deeper insight into end-of-life issues through recent studies carried out in Turkey; these studies revealed the importance of awareness-raising and education among the population on end of life issues, for which the Guide could be a useful tool.

Issues around "disproportionate" treatment were addressed throughout the whole Symposium, including the difficulty of defining what "disproportionate" treatment means, discussions with families on withdrawing life-sustaining treatment, and the importance of assistance by clinical ethicists to limit disproportionate treatment.

Conclusions

After presentations and discussion, participants in the Symposium came to the following conclusions:

1. Human dignity and human rights principles are not subject to the condition that the individual enjoys good health or has a long life expectancy. Therefore, patients at the end of life are entitled to the same dignity and rights than healthy people.
2. In Europe, the interplay of human dignity and rights has led to an increasing consolidation of patients' right to self-determination regarding health care decisions, including those relating to end of life care. This is especially important in our increasingly ageing societies, with longer life expectations, and therefore, with an increasing number of patients placed in end of life situations. In addition, the constant development of new medical technologies that prolong life contributes to create new ethical and legal dilemmas.
3. Over the last 20 years, the Council of Europe has made significant efforts to promote patients' well-being and self-determination at the end of life. The most important step in this direction was the

adoption of the Convention of Biomedicine and Human Rights (Oviedo Convention), which provides a comprehensive normative framework of principles for promoting patients' rights. The Convention is a legally binding instrument for the countries that have ratified it, including Turkey.

4. The Guide represents a further step in this same direction. The document's goal is to facilitate the implementation of the Oviedo Convention to end of life situations. The Guide summarizes the principles that could be applicable to decisions on medical treatment when the patient's life is "irreversibly threatened" in the near future. According to the Guide, in such situations the main purpose of any medical treatment is palliative, focusing on the quality of life and on pain relief.
5. The Guide emphasises that the respect of the dignity of terminally ill or dying persons implies above all the provision of only "appropriate care", enabling them to die with dignity. For this reason, "disproportionate" treatments have to be avoided. However, the Guide points out that the disproportionality of a particular measure is to be decided on a case by case basis, taking into account the development of the illness and the patient's reaction.
6. The Guide does not refer to "futile" treatments. The term "futility" has come to refer to the problems created when patients and families demand treatment that the clinicians believe to be nonbeneficial, inappropriate, or even harmful. In this context, "medical futility" is sometimes seen as a justification for the unilateral withdrawing or withholding of therapies, and in this sense "futility" is an absolutist term and tends to be system-centred. Rather, it is preferable to use the term "futility" as equivalent to "potentially inappropriate treatment" in recognition of the complex evaluation, judgement and negotiation that is commonly involved in the margins of end of life decision-making.
7. Besides the question concerning the decision of limiting or withdrawing treatments which no longer provide any benefit or have become disproportionate, the Guide points out that there is no question of discontinuing care, which is always mandatory. In this context, "care" mainly refers palliative care. Therefore, the Guide makes a distinction between "treatments", which can be discontinued if they are regarded as disproportionate, and "care", which is always mandatory.

8. Ethics consultation has proved to be a very valuable tool in the end of life decision-making process. In this regard, the long experience of German health care institutions in implementing clinical ethics consultation, which has mainly to do with end of life issues, could be very helpful to other countries.

9. In conclusion, beneficence requires that pain and other symptoms be controlled in order to provide end of life care of appropriate quality to terminally ill patients. Advance care planning, which aims to facilitate decision making at the end of life, is ethically supported by the principle of respect for autonomy. Decisions by patients or substitute decision makers to withhold or withdraw life-sustaining treatments proposed by a clinician are also supported by the ethical principle of respect for autonomy and informed consent. Both euthanasia and assisted suicide are illegal in all but a few jurisdictions. Interdisciplinary collaboration of human sciences and medicine in research is required to employ in-depth techniques with the aim to understand the needs of health professionals as well as patients and their relatives, and to provide equitable healthcare that honours human dignity. Policies of governments and institutions (hospitals, nursing homes) should serve the patients' good (principle of beneficence), promote appropriate treatment and equitable access to end of life care. Resources for end of life care, which are costly and limited, should be allocated as fairly as possible among patients.

[Please click for the Symposium Booklet \(http://www.acibadem.edu.tr/doc/EndofLifeCare-kitapcik.pdf\)](http://www.acibadem.edu.tr/doc/EndofLifeCare-kitapcik.pdf)

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PROJECT ANNOUNCEMENT "STERBEWELTEN"

A consortium of four different institutions in Vienna and Linz has started a research project on the perspective of persons at the end of life on their notion of "dying well" entitled "Sterbewelten in Österreich". The project aims to gather information in different settings and places in Austria through interviews with the persons concerned and their relatives about their

understanding of what they consider important in the last stretch of their lives.

Background of the project is an increased public discussion in the last years in Austria about the question of dying, the forms of assistance provided and the social perception of the end of life. The most significant public expression of this increased interest was the parliamentary inquiry into “Dignity at the End of Life” (2014/2015), which stressed the importance of hospice and palliative care, while steering clear of assisted suicide. The dominant discourse in Austria thus focused on strengthening palliative care and banning assisted suicide.

In view of this actual discussion, the project raises the question what the persons concerned understand by “good dying.” An “Ethics of Dying” takes into account the social need for orientation in pluralistic, secular society, where a general agreement on what is “good” at the end of life cannot simply be taken for granted. The public and political discourse is working with a strong, yet mostly implicit, normative understanding of what the factors that amount to “good dying” are. The project seeks to gather empirical data by interviewing persons at the end of life as well as their relatives and by providing an ethical evaluation of these findings.

The project has started in January 2017 and will end in June 2018. It is funded by the Anniversary Fund of the Austrian National Bank. The involved institutions are the IFF-Institute for Palliative Care and Organizational Ethics (Alpen-Adria Universitaet Klagenfurt, Wien, Graz; project lead), the research group Techno-Science and Societal Transformation (Institute for Advanced Studies), the Institute for Ethics and Law in Medicine (University of Vienna), and the Institute for Practical Philosophy/Ethics (Catholic Private-University Linz).

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NEW FULL MEMBER

Pontificio Ateneo Regina Apostolorum School of Bioethics Rome – Italy

The Pontificio Ateneo *Regina Apostolorum* was canonically established by the Holy See on September 15, 1993 and John Paul II conferred the Pontifical title on July 11, 1998. Today we have three Faculties: Theology, Philosophy, and Bioethics. *Regina Apostolorum* endeavors to form leaders in our faculties and institutes with an integral humanism capable of

bridging the gap between faith and reason, science and culture. Bringing together both our Pontifical heritage and a vanguard faculty, we aim to stand among the most acknowledged and representative institutions committed to a renewed worldview of the human person and culture.

The School of Bioethics was founded in 2001 with the inspiration to form leaders of higher education who are committed to renewing society through sincere dialogue with culture in order to infuse society with perennial human values, offering a theoretical and existential response to the interrogatives of modern men and women. With the rapid spread and application of biotechnologies, it becomes ever more evident that not only must professionals in all of the related disciplines receive adequate bioethical training.

The School of Bioethics has received students coming from all over the world and from all walks of life. The degree programs currently offered are at the Bachelor, Master, Doctoral levels, together with a Diploma program and a yearly summer course. In its 16 year of operation, over 2000 students coming from 60 countries have enrolled in the various programs offered by the School of Bioethics. Of these, over 40 have successfully defended their doctoral dissertations.

The School of Bioethics has launched a trimester open access journal since 2008, which is quasi-monographic, multicultural and interdisciplinary, with an honest Catholic identity.

The UNESCO Chair in Bioethics and Human Rights was established in 2009 and is a research arm the School of Bioethics. The institute seeks to create a forum of diverse bioethics thought leaders. Collaborating in a spirit of respect and friendship, it hopes to deliver a common framework to guide the application of bioethical principles in the light of the 2005 Universal Declaration on Bioethics and Human Rights. Its numerous activities and programs have explored the frontier areas of bioethics in relation to interreligious dialogue, neuroethics, ecology, mass media, and esthetics.

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NEW FULL MEMBER

Institute for Ethics and History of Medicine University Medicine Greifswald – Germany

The University of Greifswald, located at the Baltic Sea border in north-eastern Germany, has had a long tradition since its foundation in 1456. It is, therefore, not only picturesquely situated, but also forms one of Germany's oldest institutions of tertiary education. Western Pomerania is an area with low population density and a high proportion of elderly citizens and is often considered as a "model region" for the future development of health care services and structures. The Institute for Ethics and History of Medicine, established at the Medical Faculty in 1992, was originally dedicated to medical history, but has widened its focus into ethical topics, especially with the appointment of Sabine Salloch as a new director in 2016. The Institute's staff reflects the interdisciplinary character of the field: Philosophy, medicine, history and nursing are represented by the members of the team.

The main points of the ethics research are focused on clinical ethics, medical professionalism and decision-making, as well as on ethical issues in dentistry and ethical topics at the end of life. Current third-party funded research projects address the lived experience of health, illness and the provision of care in home nursing arrangements, and subjective views of patients suffering from hereditary pancreatic disease. Another project is analysing the theoretical and normative implications of systems medicine, and this continues the successful research on Individualized Medicine as a core theme of the Greifswald Medical Faculty. Due to its location, the historical activities of the Institute have a main focus on medicine in the former East Germany (GDR). An extensive historical collection, which is currently under renovation, places emphasis on daily medical routines and the provision of care in the era of the GDR.

With respect to teaching, the Institute is responsible for the education in the cross-sectional curriculum "History, Theory and Ethics of Medicine", which is obligatory for medical students in Germany. Furthermore, junior students are taught medical and dental terminology and its historical roots. Members of the Institute are involved in a range of additional teaching activities within and beyond the Medical Faculty. Interfaculty activities in research and teaching are structured under the head of a "Department of Ethics, Theory and History of Life Sciences (DETGeLWi)", whose activities aim at connecting and supporting various scientific domains examining questions of medicine and life sciences. The DETGeLWi provides the interface between clinical practice and ethical theory and was also the nucleus for the establishment of a Clinical Ethics Committee at the University Hospital, where currently – particularly within clinical ethics consultations – ethical problems

are discussed between the professions, patients and relatives involved.

We at the Greifswald Institute, which became an EACME member in 2016, are looking forward to new contacts and vibrant exchange with colleagues from other European institutions and we are hoping to meet you soon in Greifswald or elsewhere!

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THESIS ABSTRACT

Extended Bodies

An empirical-philosophical study to women's bodily experiences in breast cancer

Many women with breast cancer face the physical consequences of medical treatments, such as scarring, breast loss, lymphedema, hair loss, nausea, pain, fatigue, stiffness of the joints, increase in body weight, heart problems, and loss of bodily functions. Within this dissertation, Marjolein de Boer researches the bodily experiences of women with breast cancer, and the ways in which they give meaning to their changing life and body.

There is a vast number of empirical studies about women's breast cancer experiences. These studies either predominantly discuss women's psychological and subjective ways of coping with a new body, or how their social environment shapes their illness experiences. In combining these different approaches, this study explores how subjective breast cancer experiences are shaped within and through the contexts in which they arise.

This analysis of illness experiences takes place against the background of a phenomenological understanding of embodiment as open to the world. Phenomenology teaches us that our embodied experiences are shaped by elements outside of our physical body, that is, by our lived contexts. We live as *extended bodies*. This dissertation focuses on four (out of many) contexts through which people may extend themselves, namely material, social, narrative, and temporal contexts.

In analyzing women's contextual breast cancer experiences, this study uses phenomenology also as a methodological approach in qualitative research.

Women experiences and sense making structures are teased out in individual interviews with women, in interviews with women and their partners, and by analyzing personal breast cancer blogs.

By building on theories within philosophy of technology, **chapter two** explores how women's agencies are shaped through their engagements with breast cancer technologies and artifacts. It is revealed that women's agencies – understood as their capability to act and perceive in the world – is not only shaped by their material context, but that women also shape this context, and thereby their own agency.

In **chapter three**, De Boer explores how women's experiences are shaped within and through the illness stories they tell on their personal weblogs. While blogged narrations seem to enable women to resist and substitute prevailing cultural norms about breast cancer – norms that dictate a return to a healthy life with an unmarked, feminine body –, women's blogs also tend to be interspersed with efforts to establish such an everyday embodied life.

Chapter four focuses on women's social context, and more specifically, on the ways in which an intimate relationship shapes breast cancer experiences. Although sharing illness experiences is revealed to be a constitutive dimension of what it means for couples to live with and through breast cancer, it does not come naturally. For couples, sharing involves complex affective and/or bodily encounters, whereby the fault lines that both separate partners into individual selves and join them together as a mutually reliant unity are continuously and actively debated and negotiated.

Finally, in **chapter five**, De Boer attends to the significance of women's lived temporal dimensions by exploring how breast cancer experiences take shape through women's expectations about their breast reconstruction. In formulating and re-formulating expectations, women set themselves the difficult, and sometimes impossible task of filling in and anticipating that which by definition unknown and always – to a certain extent – a surprise: their future. Difficult as it may be, this kind of temporal extendedness is crucial for women and their sense making efforts within this reconstructive trajectory.

On the basis of these empirical studies, three general structures of what extended embodiment in breast cancer means are revealed: (1) women's embodied experiences encompass specific appearances of multiple sensory aspects, such as those of visibility and tacility; (2) women's experiences are not only passively extended and shaped by their contexts, but women are also actively involved in the ways in which they are extended; and (3) for many women, giving

meaning to bodily experiences within and through their lived contexts involves endeavors to be normal, and thus, their experiences cannot be seen apart from a larger prescriptive cultural context.

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ADOLESCENTS: CAPACITE DE DISCERNEMENT ET/VS AUTORITE DE DECIDER

La question de la liberté des adolescents de prendre de manière indépendante de leurs représentants légaux des décisions concernant les soins est un classique en éthique médicale. Dans les décennies récentes, l'accent a été mis sur leur capacité de discernement croissant avec l'âge et leur compétence décisionnelle (il est indiscuté, pour le moins, qu'*on doit prendre attentivement l'avis des enfants, même très jeunes, et en tenir compte*). En Suisse, le droit de demander et recevoir (ou refuser) des soins est dit par le Code civil un *droit strictement personnel*, que le mineur doué de discernement exerce librement, y compris à l'insu ou contre le gré de ses parents. Des questions délicates à cet égard sont par exemple en rapport avec la contraception et l'interruption de grossesse ; les réponses données varient selon les pays. D'autres interrogations portent sur l'éventuel don d'organe par donneur mineur vivant, ainsi que sur l'assistance au suicide - en Belgique en 2016 il a été admis qu'un mineur pouvait légitimement requérir un tel geste - y compris euthanasie.

En général, la doctrine ci-dessus ne semble pas aujourd'hui poser problème en Europe occidentale (notamment nordique). Raison pour laquelle il est intéressant de trouver, dans une récente livraison du *Hastings Center Report*, un article détaillé (1) d'une enseignante de l'Université de St. Louis (USA) qui en prend le contre-pied, argumentant que la décision devrait rester avec les représentants légaux. Elle note que l'évidence scientifique est imprécise : « Les mêmes données psychologiques et neurologiques ayant été interprétées en soutien à des conclusions opposées, il paraît prudent de réserver son jugement quant à ce qu'elles révèlent de la qualité de la prise de décision par les adolescents.

Le propos est parfois simpliste: «Un enfant de dix ans peut disposer du discernement voulu pour décider de recevoir un médicament en une ou plusieurs doses mais pas de la capacité de décider si sa jambe gangrénée doit être amputée.» Dans ce sens, je prenais dans des exposés à ce sujet l'exemple suivant : en principe (sauf objection de conscience), le

médecin peut/doit répondre à la demande de contraception d'une adolescente de 15 ans (et respecter le secret médical, y compris vis-à-vis des parents) ; mais il ne saurait obtempérer de la même manière si elle lui demandait, « parce que le monde va si mal et qu'elle ne voudra jamais d'enfant », de la stériliser... Le principe (juridique et éthique) est « en faveur » de l'ado, le praticien toutefois garde un devoir professionnel d'appréciation (2).

« Avec d'autres, dit Salter, j'argumente que les parents devraient garder l'autorité de décider. Je ne le dis pas parce que je croirais que la plupart des ados n'ont pas la capacité de discernement voulue [mais] parce que, en soi, la capacité de détermination d'un ado ne justifie pas à mon sens que l'autorité de décider doive lui être remise. Confondre capacité et autorité néglige une raison centrale : les parents sont moralement et légalement responsables pour leurs enfants ». Aussi : « Il se pourrait que la science montre que certains ados prennent de décisions aussi bien que leurs adultes de référence. Mais savoir si les ados doivent se voir accorder l'autorité de décider est une question éthique qui n'est pas réductible à l'évidence scientifique. »

Il y a là une vraie différence socio-culturelle. La société étatsunienne et ses valeurs ont des dimensions legalistes marquées ; de plus, on observe un certain retour vers l'autorité de ceux qui la détenaient traditionnellement – noter aussi que Salter parle de la famille comme d'une unité « sacrée » de la société. En Europe, l'éventail des références pertinentes montre un autre équilibre, une appréciation différente des intérêts et droits respectifs. Je pense pour ma part que nous sommes mieux servis par une disposition légale sur le droit personnel librement exercé par l'ado capable de discernement (sauf exception), et par la position éthique correspondante, que par des règles sans souplesse. Point qui semble contradictoire : la demande de Salter de maintenir de routine l'autorité parentale de décider pour les ados fait référence à des éléments comme l'âge chronologique et la majorité juridique, rigides par essence, alors que par ailleurs elle insiste sur le caractère éthique de la problématique.

1. Salter E.K. Conflating capacity and authority : Why we're asking the wrong questions in the adolescent decision-making debate. Hastings Center Report 2017, 47, No. 1, 32-41

2. N.B. ici : en cas de désaccord/conflit, l'ado exerce son droit strictement personnel de décider. Néanmoins, le dialogue doit être favorisé, *chaque fois que c'est possible*, en vue d'arriver à un assentiment des représentants légaux.

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BOOK REVIEW

“Bioethics: A Philosophical Introduction, Second Edition by Stephen Holland” Published by Polity Press, Cambridge, UK, 2017
272 pages. Price (Paperback): £17.99 / €23.32

Bioethics is a multi-disciplinary endeavour, and it has never been *de rigueur* to have a philosophical background to work within the area. Indeed, given bioethics is offered as a discipline in its own right at all academic levels, it is quite possible to remain within the bioethical bubble from the beginning to end of an education career. The question remains as to the weight that philosophical knowledge should carry in bioethical discourse. A browse through the bioethics journals suggests philosophy is readily observable in some discussions, much less so in others. This patchiness is a shame because philosophy has great powers to clarify debates and conceptualise language. As such Holland's book works on a number of levels. It is a welcome introduction that should be approachable for students of all levels. This notwithstanding, it will be of particular interest to those students who have got beyond the basics of normative ethics and are seeking to study some applications of these theories. It is also a good refresher for those of us (and I include myself in this category) who 'get by' and/or dabble at the edges of philosophy. Finally, since Holland injects a good deal of original thinking into his arguments (especially in his discussion of the normativity of the 'natural'), this introduction stands as a noteworthy contribution to his chosen areas, rather than 'just' a reformulation of existing argument.

The book is written in an accessible style. When I studied for my doctorate, a fellow student with a philosophical background advised me how to read philosophy. She said a philosophical work should be read at least twice. The first read should approach the work like a novel, while the second should be a deep, critical, reading. I always found this difficult advice. The instinct to ponder at the first reading was too great, destroying my momentum. I did not find this the case for Holland's book. While there is much to ponder upon, Holland's style is as near as philosophy can come to breathless. Indeed, the book carries the reader through a remarkable range of argument at a sometimes breakneck pace. Given this, it is impressive that what is gained in style is not lost in depth, and, while it is doubtful that the arguments voiced in this work will be the last word in the matter, they are, as I

say, given in sufficient depth to open the door on more serious study.

The book is structured around four distinct areas. In each of the four, Holland considers two or more bioethical problems, and uses these as a frame to introduce and explore philosophical viewpoints on a particular area. As the book proceeds, the philosophical arguments from preceding sections recur in new contexts giving the reader the opportunity to consider them in a fresh light. This is satisfying, although it means the reader will make the most of this book by reading it as a whole, rather than selectively. At around 250 pages, this should not present a serious problem to most readers. The first part of the book introduces two innovative biomedical procedures: stem cell research and xenotransplantation. It then considers the nature of the moral status of persons, and whether embryos and/or animals should therefore be accorded or denied rights or interests in line with such a status. Using these insights arguments are then made about the ethics of stem cell research and xenotransplantation. While the discussion is ultimately inconclusive, it does much to clarify some of the issues at stake in these debates.

The second part of the book builds on these themes of moral status. It considers the concepts of life and death as they apply to medical non-treatment, euthanasia and assisted suicide. These topics are discussed using arguments about the value of life, definitions of death and the putative distinction between killing and letting die. Given the intractability of this topic area, Holland's stated intention is to use his discussion to reflect on the steps bioethicists should take when confronted with implacable principles of seemingly equal moral weight. Nevertheless, Holland's conclusion – treat situations on a case by case basis – is not entirely convincing. Surely, one is confronted by these implacable principles in each individual case? The ability of philosophy to clarify is indisputable. Yet this section raised questions about why philosophical contributions to bioethics should be necessary if solutions would ultimately be made on the basis of intuition in each case. This seems a rather crucial question and it was a shame that it was not engaged with in a thoroughgoing manner. Indeed, one might question the purpose of seeking clarity since bioethics – in often seeking spaces for broad compromise – at times appears to actively welcome conceptual *unclarity*. There is thus a danger that the whole philosophical contribution to bioethics might thereby unravel.

In the third part, Holland considers the nature of personal identity. Personal identity is discussed in relation to the main areas in which it raises bioethical questions. The first of these is whether identity altering

interventions in prenatal genetic testing result in a different person being born. The second questions the moral authority of advance care planning where there are significant changes between the past and current identity of the patient. This latter issue is first considered in relation to patients with dementia and permanent vegetative state, and then, in more depth, to the minimally conscious state. Again this structure allows earlier arguments about moral status and the value of life to be effectively reconsidered. The sustained attention to disorders of consciousness also furnishes a more rounded and conclusive ending to this section.

The final part of the book considers the normative potential of appeals to naturalness or unnaturalness. Holland does so by considering three areas related to human reproduction: established methods of managed reproduction (such as in-vitro fertilisation and surrogacy), selection of traits through genetic enhancement, and human cloning. The discussion reprises and adapts a theory developed by Richard Norman, and makes for interesting reading. In many ways this is both the most satisfying part of the book, as it engages with a stimulating and (to me) hitherto unfamiliar topic. Indeed, Holland suggests it has been selected because it is an argument that is rare within bioethical circles, yet frequently heard without. This is appealing as it would seem important that bioethics attend to problems raised in public (by which I mean non-academic) discourse as well as those of within academic (and clinical) bioethics. Nevertheless, despite this satisfaction, this section of the book felt slightly out of place. In contrast to the earlier sections, it was built much more lightly upon established bioethical debates, the arguments felt looser and more experimental, and the repeated recurrence of key academic protagonists (particular Richard Norman, but also Mark Sheehan) made this section feel more like an extended paper than a logical continuation of the previous sections.

Naturally others will note additional omissions (for example, ethical theories are barely considered), but those I have highlighted seem entirely forgivable given the focus and length of this work. Some will also disagree with Holland's choices of topic, and perhaps more with his conclusions, yet this is surely the essence of a good bioethical work. Overall I suggest this book does a wonderful job of signposting key philosophy in a range of areas, and is therefore a fine achievement.

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BOOK REVIEW

Jonathan Glover

Questions de vie ou de mort

Labor et Fides, Genève, 2017, 386 pages

CHF 29.00 / € 24.00

Les Editions Labor et Fides offrent une excellente occasion de se familiariser en français avec le travail majeur du philosophe britannique Jonathan Glover (1941). Ce qui surprend, c'est que la publication originale ([*Causing Death and Saving Lives*](#)) date de 1977, mais le propos n'a pour l'essentiel pas vieilli. Ce livre est une somme sur les questions « qui se posent lorsque l'on envisage d'éliminer ou, au contraire, de sauver des vies humaines » - première ligne de la préface qui pourra faire froncer le sourcil (voire qui détournera de la lecture – ce serait une erreur). Tout en restant pluraliste, il est vrai que l'auteur présente des conceptions représentatives de la bioéthique anglo-saxonned'orientation conséquentialiste/ utilitariste, qu'il est très intéressant de comparer aux positions prévalant en Europe continentale.

« Nos attitudes à l'égard du suicide, de l'euthanasie, de la peine de mort et de la guerre ne peuvent pas être traitées rationnellement si on les considère de façon radicalement séparée les unes des autres. » Etonnant... fondamentalement correct. Le but est « d'aboutir à un système de réponses non contradictoires couvrant l'ensemble des questions relatives au faire mourir, en excluant les formes opposées d'absolutisme éthique » que sont l'interdiction totale et la permissivité totale. Ceci en rappelant que « faire mourir l'autre » est admis dans certaines circonstances (légitime défense, pour beaucoup en cas de guerre, et - de plus en plus refusée - peine de mort). L'auteur discute dans diverses parties de son étude de la notion de « vie digne d'être vécue », qui peut susciter la réserve voire le rejet. Même si ce thème semble de la nature d'un indécidable, il doit à mon sens être débattu de manière différenciée, pondérée ; d'autant plus aujourd'hui qu'il y a 40 ans, vu les défis voire les crises liées aux évolutions récentes de la médecine, de la maladie, du mourir.

Glover distingue deux grandes catégories : les problèmes émergeant dans le contexte médical (y compris l'attribution des ressources qui ne sont disponibles qu'en faible quantité) et ceux qui se posent dans des contextes socio-politiques généraux : guerre, peine de mort – discutant aussi la question de la grève de la faim (en adoptant l'attitude acceptée aujourd'hui que la personne capable de discernement ne doit pas être alimentée de force – voir pp. 201-209). Il se

penche sur la doctrine de la vie sacrée (sans y adhérer), sur la question des fins et des moyens (théorie du double effet), et sur celle de l'inaction et de l'indifférence (actes et/vs omissions).

Dans la partie principale du livre « Problèmes d'éthique appliquée », sont abordés d'abord les sujets classiques : l'avortement - du point de vue du fœtus (quand devient-on une personne ?) et du point de vue des femmes et de leurs droits; l'infanticide ; le suicide ; l'euthanasie (avec ou sans demande/consentement du patient concerné) ; la sélection des personnes/patients (depuis la parution de l'ouvrage, les transplantations d'organes et la procréation médicalement assistée notamment se sont ajoutées à cette liste, et les questions autour de la fin de vie se sont aiguisées). Puis viennent des chapitres détaillés sur la peine de mort et sur la guerre.

Sur un sujet actuel: « Il n'est pas évident qu'il faille penser l'euthanasie en termes d'alternative aux soins palliatifs : pourquoi ne pas l'envisager comme un complément ? Un hôpital dans lequel on pratique des euthanasies volontaires peut très bien avoir du personnel faisant tout ce qu'il peut pour rendre inutiles les demandes d'euthanasie ». Aujourd'hui des voix s'élèvent dans ce sens, d'autres y sont farouchement opposées... Point d'importance : « La question de savoir si l'on doit mettre en place un système très formel de validation des demandes d'euthanasie. D'un côté certains prétendent que des signatures de témoins fournissent des garanties. D'un autre, les procédures bureaucratiques constituent une interférence dans la relation unissant les patients aux médecins. Il me semble préférable d'avoir confiance dans l'idée que les médecins n'ôteront pas la vie de patients de façon injustifiée et [suivront des normes] de déontologie. »

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WHY I WROTE 'EMPIRICAL BIOETHICS: PRACTICAL AND THEORETICAL PERSPECTIVES'

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First, it's important to note that I did not write it. The book is an edited collection, and therefore written by multiple contributors. I did, however, co-conceive and co-edit it with Mikey Dunn and Alan Cribb, and so in this short piece I will reflect briefly on why we felt such a book was needed – and why I felt sufficiently strongly about it to spend nearly five years chivvying it along.

Empirical Bioethics: Practical and Theoretical Perspectives was conceived in a pub. I was spending some time in Oxford, as a visiting scholar at the ETHOX Centre. I had just presented a draft paper about Reflexive Balancing (1), and Mikey Dunn and I were having a quiet drink at the end of the day and reminiscing about when we were postgraduate students embarking on empirical studies without a clue about how to bring together the empirical and the normative in our nascent theses. 'Don't post-graduates have it easy today', we thought, 'now that there is so much methodological literature about empirical bioethics'. Pausing to reflect on this for moment, we realised that it was nonsense.

At the time I was also developing and delivering a teaching module on an intercalated ethics course (at the University of Birmingham) on empirical bioethics, and attempting to teach, from scratch, both why empirical bioethics developed and how to do it. Why was I finding it so difficult if the abundance of literature made it so easy?

The answer, we felt, lay in the fact that the literature was published widely and in different places, and tended to focus on either the general rationale for empirical bioethics, or on outlining specific examples of how to do it. Both of us had written both kinds of paper, but we had begun to see the problem with the absence of joined up thinking that showed the links and relationships between aims, methods and epistemology in a non-partisan way (or at least in a way that did not push a particular approach). What we needed, we decided, was a book that could introduce and explain the epistemological and methodological complexities of empirical bioethics, but that had a strong editorial line that tried to make sense of it all and put it into context. Our thinking here was later confirmed at a meeting of the Interdisciplinary and Empirical Ethics Network (IEEN) on learning and teaching, in Birmingham 2012. Two undergraduate students described their experience as learners, which was described thusly in the workshop report:

"[they said that] inexperience makes engagement with the literature and methods difficult, and they found themselves, whilst trying to learn 'how to do bioethics', lost in a sea of competing disciplinary aims, methods, outcomes and ideas." p73 (2)

By this time, of course, we had already begun to propose the book to Cambridge University Press – but it was nice to have our rationale confirmed.

Once we had conceived the idea, Mikey and I realised that we lacked experience editing books, and felt that we needed to bring on board someone who both had experience and wide knowledge of the field. Alan Cribb, my co-chair of the IEEN, seemed the perfect person. Serendipitously, when we approached Alan it turned out that he had already conceived a similar idea independently, and was looking for ways to develop the idea.

Once we had formed our tri-partite editorial team we began to think about how to shape the book. This was no mean feat, and the debate went on for a while. The difficulty we had was that we saw empirical bioethics in holistic terms, but in putting together a book we had start somewhere, and this required us to impose a structure on how the field should be understood. Given that we wanted to produce a book that could be used by novice empirical bioethics researchers, we had to find a starting point and build from there. We ended up splitting the book into two sections, looking at 'theoretical' and 'practical' issues. However, as we ended up noting in the preface:

"This distinction is somewhat artificial and reflects differences in emphasis rather than anything more clear-cut. It is a product of the need to find a way to structure the book and is not a statement about the order in which questions ought to be approached, or which perspectives ought to be prioritised. In fact, as editors of this volume, our position is that the theoretical and practical considerations outlined herein cannot be separated. This is very much part of the excitement and challenge of the field: to find ways of approaching substantive moral questions which matter to practical actors, whilst taking seriously both the demands for rigour that properly attach to different forms of academic research and the theoretical and philosophical debates that inform these demands. We hope this book will help other researchers engage with, and confront, this challenge" pxii (3)

Once we had a structure, we then had to get authors on board. We were very fortunate that the book concept was met with huge enthusiasm and willingness to commit precious time to writing. I am sure that writing for this book was a frustrating process, given that we, as editors, had a very clear idea of what we wanted from each chapter so that we could create a coherent narrative around the book's content. Again, we were fortunate that all our

contributors were very accepting of this, and stayed on message. The result, I hope, is worth reading.

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