

EACME Newsletter

European Association of Centres of Medical Ethics

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EDITORIAL

It seems after two successive years when UK medical ethics found itself in the international spotlight over cases of withdrawal of medical treatment over spring and summer, it is now the turn of France. The case of Vincent Lambert, a 42-year-old man in a continuing vegetative state (CVS) after a road traffic accident, from whom his doctors proposed to withdraw the tube feeding that was keeping him alive, once again saw the courts settling a family, and societal, disagreement. Vincent's parents and two of his siblings opposed withdrawal of treatment, while Vincent's wife and six other siblings agreed that withdrawal would have been in accordance with Vincent's past wishes. The case was the subject of public protests and impassioned debate that appeared little changed from that which in the past accompanied similar cases internationally, such as Terri Schiavo in the USA, Eluana Englaro in Italy and Anthony Bland in the UK. Those who supported withdrawal argued that a life in CVS was so diminished patients could not experience anything, be it pain or joy. Such a life was not worth living on its own account, and furthermore, that the past wishes of the patient should be followed in such cases. Those who opposed withdrawal argued that life had an intrinsic value, that there was no way of telling what the patient with CVS would want contemporaneously, whatever their wishes in the past, but that withdrawal of nutrition and hydration from somebody who was not actively dying was both illogical and unspeakably cruel. These arguments are essentially the same as those heard in every similar case in the past forty years. Despite this apparent repetition, all this seems to have some value. It highlights the important work of bioethicists, amid extremely emotive issues, to help the public to look rationally at the world, so the world looks rationally back (to paraphrase Hegel). This is not to say that rationality is the end of the story – the importance of emotion in being a full human being has been rather too little stated

in philosophical bioethics – yet the complex role of rational argument as a glue that strengthens a society's ability to find acceptance amid emotive disagreements shows that bioethics can have an important function.

It is therefore not without some (positive) emotion that I present the latest EACME newsletter. As you shall see the newsletter covers an impressive and broad range of activities and reports, including a discussion of empirical bioethics in Peru and reports on research projects as diverse as the ethics of genome editing and the evaluation of clinical ethics support, as well as book reviews and workshop reports. I hope you enjoy these, and I am looking forward to meeting many of you in Oxford this year for the EACME 2019 conference, in what promises to offer both healthy debate, rational deliberation and (hopefully) some joyous moments!

Dr Giles Birchley

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NEWS FROM THE EACME BUREAU

We are very excited to approach this year's Annual Conference and look forward to getting inspired by the historical city of Oxford with its beautiful colleges and gardens. As you will have seen in the EACME News, this year we will elect one new full member and one associated member to join the EACME board. The elections will take place during the General Assembly on Friday 13th September 2019. Please join and give your vote to help us shaping the future of EACME.

We have also been thinking ahead and already started preparing next year's conference which will take place in Cluj, Romania. In June, the bureau met with Maria Aluas who introduced us to her conference team and showed us the locations where the conference will take place. Maria and her team are well on track with the preparations and everyone, including the Dean of the Medical School, was very welcoming and supporting of the EACME Conference. We could feel a real excitement to develop medical ethics in Romania. Cluj is a major university city with a very young and vibrant vibe, and we were very excited about the opportunity to host our next conference there. Maria will say more about it at the closing session in Oxford!

We wish you a restful summer and look forward to seeing you next month in Oxford,

Ruth

On behalf of the EACME bureau (Rouven, Bert, Angelique)

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EACME CONFERENCE 2019

Dear Colleagues,

We look forward to welcoming you to the University of Oxford from 12th-14th September 2019 for the 36th EACME conference in Oxford, which will be on the theme of *Rethinking Ethics in 21st Century Europe*. The conference is being hosted by The Ethox Centre and Wellcome Centre for Ethics and Humanities.

The emergence of bioethics in the 20th Century made a major contribution to the achievement of higher ethical standards in healthcare practice and medical research. Despite these valuable contributions however, new challenges are increasingly being presented to established ways of thinking in bioethics by advances in neuroscience, big data, genomics and global connectedness, and by their convergence. Personalised medicine and big data approaches in healthcare systems are changing the focus of medicine and increasingly blurring boundaries between clinical and research activities. Together, these developments raise important questions about the extent to which 20th Century ethics continues to be fit for purpose.

In addition to these changes in technology, Europe is also undergoing a shift in research agendas and a redefinition of normative as well as national boundaries in Europe (yes, we are thinking of Brexit here!), and beyond. These changes raise the question as to whether medical ethics in the 21st century needs to revisit its principles and approaches to be adequate to

the tasks with which it is confronted. Do we need to rethink bioethics for the 21st Century? The 2019 EACME conference in Oxford will address this and related questions, and respond to a pressing need for ethics, humanities and social sciences research on these new challenges.

We hope that as many of you as possible will be able to join our conference and contribute to these important discussions. We would like to thank everyone who has submitted an abstract and who has already registered. Those who have not registered yet, but would like to, can do it [here](#). The keynote speakers and all the submitted abstracts promise a very exciting programme which can be accessed online [here](#). (Please note, the programme may change between now and the conference.)

Our **plenary sessions** will be the following:

Professor Christoph Rehmann-Sutter, Prof. Dr. phil., dipl. biol., Professor for theory and ethics in biosciences, Institut fuer Medizingeschichte und Wissenschaftsinstitut, University of Luebeck, Germany (title t.b.c.)

Professor Annelien Bredenoord, Professor of Ethics of Biomedical Innovation UMC Utrecht, Department of Public Health, Healthcare Innovation & Evaluation and Medical Humanities (PHM): *Ethics parallel research: evaluating the ethics of new technologies*

Professor Nikola Andorno-Biller, Professor and Director of the Institute of Biomedical Ethics and History of Medicine, University of Zurich: *'Deep ethics': How machine learning can support moral decision-making in health care*

Professor Richard Ashcroft, Professor of Bioethics, Queen Mary University of London, School of Law: *Public Health Ethics in an Age of Populism: Rethinking the Role of National Policy in the Face of Emerging Diseases*

Conference Themes are:

Ethical and Social Impact of New Technologies

- Big Data
- Genomics
- Neuroscience
- Reproduction

(Re)defining Boundaries and Borders

- Regulation and law
- Education
- Infections and drug resistance
- Beyond Europe

Ethics in Contexts

- Austerities
- Emergencies
- Clinics
- Communities

(Re)thinking Traditions and Identities

- Rethinking Professions and Roles
- Patients and Publics
- Nature and Practice of Bioethics
- History, Politics and Values

We look forward to welcoming you in September in Oxford,

Mike Parker & Ruth Horn, on behalf of the scientific committee

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“PROFESSIONAL ETHICS AT THE END OF LIFE. INTERNATIONAL COMPARISONS”

International Workshop for Young Scholars 27th May – 1st June 2019, Greifswald (Germany)

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1. Background

In caring for seriously ill and dying patients and their relatives, professionals are likely to face a myriad of complex and challenging ethical questions. Like all medical care, care for those nearing the end of life is embedded within a broader socio-cultural environment. However, sensitivities surrounding death and dying, as well as growing older populations in many European countries, add additional complexities to care at the end of life. Alongside their patients, professionals must navigate the ethical dilemmas presented when death becomes expected rather than avoided. End-of-life care is holistic, encompassing the physical, psychosocial, spiritual, and emotional. Each professional involved in this multi-disciplinary care, whether they are a physician, nurse, pastoral carer, volunteer, or someone else entirely, carries with them their own set of values. Furthermore, research on the practice of end-of-life care is carried out in a wide range of normative and empirical disciplines, including philosophy, law, theology, medical ethics, sociology, and psychology. This diversity in norms and values can result in inter- and intra-professional challenges in everyday practice with the

potential for the cultural attitudes of those caring for seriously ill and dying people to differ significantly.

Against this background, the Institute of Ethics and History of Medicine at the University Medicine Greifswald hosted an inter-disciplinary workshop on "Professional Ethics at the End of Life." The international workshop funded by the German Federal Ministry of Education and Research (BMBF) took place from 27th of May – 1st of June 2019 in the old fishing village of Wieck (Mecklenburg-Western Pomerania, Germany). The participants were selected competitively based on their submitted abstracts. Under supervision of Sabine Salloch and Anna-Henrikje Seidlein, young researchers (PhD students and young postdocs) from a diversity of healthcare-related disciplines and professions were brought together to discuss professional ethics at the end of life and to identify current ethical challenges within this field.

2. Activities and content

The week-long meeting included two expert workshops, a public lecture, and presentations from thirteen young scholars.

Expert workshops

Marta Spranzi (Paris, France) argued in her workshop on "Professional integrity at the end of life", that end-of-life practices - such as withholding or withdrawing treatment, euthanasia, or terminal sedation - and the corresponding ethical considerations depend to a great extent on what is considered to be the physicians' attitude towards death and their duty towards patients and their families. The concept of medical professionalism is thus of paramount importance to understand end-of-life issues and to elaborate guidelines and norms that should regulate practices in this domain. She organised a discourse on arguments about whether supporting patients in assisted suicide is compatible or incompatible with medical professionalism.

Christine Dunger (Witten/Herdecke, Germany) ran a workshop on "Nurses' professional role in end-of-life care". She invited participants to consider how perspective and experience influences professional understanding of nursing practices, as well as the setting and environment in which these practices take place. Nurses' roles and duties regarding decision making at the end of life, a key situation in view of professionalism, vary widely between countries and can depend on different professional behaviours and values. This workshop was designed to bring together participants from different countries and backgrounds to explore how context and perspective changes the frame through which nursing is seen.

Public evening lecture

Professor Eric Vogelstein (Pittsburgh, US) analysed in his public evening lecture "Professional-Role Obligations and Assisted Dying" the ethics of medically-assisted death (MAD) with respect to physicians' roles and the moral obligations which those roles entail. His main emphasis concerned the question of whether physicians' professional role incorporates moral obligations not to participate in MAD. He investigated whether it is something special about being a physician which means they ought to refrain from participating in MAD. Vogelstein argued that there are no convincing professional-role-based teleological or non-teleological arguments against physicians to practise MAD.

Participant contributions

The workshop began with a talk and discussion about the ethical dilemmas raised when informal caregivers are paid for their work, presented by PhD student Christopher Poppe. Reflecting on the blurred boundaries between employed and volunteered caregiving, participants discussed the uncertainty of the consequences for patients when legislation shifts societal perspectives on what it means to be a caregiver. The concept of uncertainty was returned to in different forms throughout the week, with participants sharing examples from their research and from interactions with colleagues, patients, and families. Elodie Camier-Lemoine discussed the uncertainty of death from a philosophical perspective, suggesting that the individual nature of experiences of death challenges the practice of empathising with those who are dying. Sharing research findings from a clinical setting, Bradley Lonergan also described how uncertainty of outcomes for patients in an intensive care unit setting is dealt with using Time-Limited Trials. In the discussion that followed, participants reflected on how uncertainty in that setting may serve a different purpose for those involved; whereas families may rely on uncertainty for hope and a chance to say goodbye to relatives, professionals may see uncertainty as a challenge to respond to.

Other presentations explored roles and responsibilities, recognising that the ability of professionals to navigate through difficult end-of-life situations is limited or facilitated by organisational culture. Eva Kuhn explored responsibility in the context of spiritual self-care for professionals working in end-of-life care, a particularly emotionally charged environment where professionals should be encouraged and provided space by organisations to care for themselves. This shared responsibility for professional development was also evident in survey findings presented by Andreas Mues on attitudes and strategies to cope with ethically challenging end-of-life situations amongst hospital-

based professionals; the often-limited medical ethics education in clinical training and the role of on-the-job learning was also discussed. A different methodological approach revealed a new angle on this theme: Mara Kaiser's narrative inquiry on disgust in a hospice setting highlighted the importance of honest, collaborative reflection between professionals when responding to ethically challenging situations. Her research and presentation also drew upon the power of patient stories and shared narratives to help find resolutions to difficult situations.

Ethical issues for professionals trying to understand and respond to patient preferences about death and dying in fair and appropriate ways were also raised at several points. The socio-cultural setting was an important influence in many instances. Joelle Azzopardi described preferences among Maltese cancer patients for a more paternalistic approach than that typically promoted in many other European countries. Sharing his experiences from Brasil, Guilherme Gryscek also outlined a paternalistic approach to medicine there which, alongside societal negative attitudes towards ageing, shapes the way patient preferences are taken into account. In other ways, the findings from Malta were similar to what has been reported elsewhere in Europe; patients tend to like to be informed about their cancer diagnosis but there may be a preference for a more passive role in decision-making amongst patients who received less education. A review of literature from the UK about palliative care referrals presented later in the week by Maddy French also found that socioeconomically disadvantaged patients may experience challenges expressing preferences, perhaps related to less awareness of palliative care services. Complexities around both assessing and meeting patient preferences were also evident in a talk on organ donation in the UK from Natalia Kyrtata. Central to the discussion was the ethical dilemma of whose wishes come first after someone has died, the deceased patient or the family, and how the opt-out organ donation policy recently adopted by the UK might affect this.

Towards the end of the week the group reflected further on patient autonomy and care preferences with a day of talks dedicated to the topic of Advanced Care Planning (ACP). Sharing findings from her interviews with people with dementia, Johanna Henrike Voß invited participants to think about the ways such patients can remain attached to life as their disease develops, and how the language and tools of advanced care planning can be adapted to support them. Roland Simon presented a critical reflection on the ethical principles that underpin ACP, such as autonomy and quality of life. His presentation and the subsequent discussion emphasised the importance of perspective when discussing quality of life, arguing that people have

different understanding of 'quality' and may also change their attitudes at different points in their lives. Ending the week, Anne Volmering-Dierkes talked about the influence of scientific and political discussions about ACP on societal attitudes and clinical practices. Presenting results from a critical discourse analysis, she found there was little space for public critical voices about ACP and argued that a lack of room for broad perspectives is detrimental to research and healthcare.

3. Conclusion

Although united around the topic of ethics at the end of life, the workshop participants were diverse in their professional backgrounds, areas of interest, and research methodologies. Rather than a barrier to discussion, this broadening of perspectives helped participants delve deeper into the issues at hand and highlighted the importance of inter-disciplinary conversations. By the end of the workshop, there was a shared understanding about some key characteristics of professional ethics at the end of life, including inter-professionalism, socio-cultural-political contexts, core principles of palliative care, and responding to conflict and uncertainty. The workshop participants were appreciative of the opportunity to think about how their own work fits in with the broad research field on ethics at the end of life and are now working on a joint position paper as well as several collaborative articles to continue the discussion.

Organising team: Anna-H. Seidlein and Sabine Salloch (both Greifswald, Germany)

Young scholars: Andreas Mues (Berlin, Germany), Anne Volmering-Dierkes (Düsseldorf, Germany), Bradley Lonergan (Lancaster, UK), Christopher Poppe (Basel, Switzerland), Elodie Camier-Lemoine (Lyon, France), Eva Kuhn (Munich, Germany), Guilherme Gryscek (Sao Paulo, Brazil), Joelle Azzopardi (Msida, Malta), Henrike Voß (Heidelberg, Germany) Maddy French (Lancaster, UK), Mara Kaiser (Berlin, Germany), Natalia Kyrtata (Lancaster, UK), Roland Simon (Osnabrück, Germany)

Senior researchers and experts: Christine Dunger, PhD (University Witten/Herdecke, Germany), Prof. Eric Vogelstein (Duke University, US), Prof. Marta Spranzi (Université de Versailles Saint-Quentin-en-Yvelines and Center for Clinical Ethics AP-HP, France)

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THE PATH TO FOSTERING GOOD SCIENCE: THE EMBASSY OF GOOD SCIENCE

Iris Lechner, Natalie Evans, Guy Widdershoven, Amsterdam UMC

The Embassy of Good Science, a novel online platform for research integrity and ethics, was launched at the World Conference on Research Integrity in Hong Kong past June. The Embassy aims to bring together all available existing resources on research ethics and research integrity and develop new, unique content. For the past two years the platform has been under development, and is now live at www.embassy.science

The Development

The idea of the Embassy of Good Science, or 'Embassy' for short, was born three years ago. There was, at the time, no website that compiled the often complex information, guidelines, rules and tools on how to foster the best research practices. A platform that was easy to navigate and improved daily research practice was (and is of course) much needed. The goal of the Embassy is to create an outstanding online platform for research integrity and research ethics. A proposal for a project was prepared by a consortium including several EACME members: VUmc (now Amsterdam UMC) as coordinator, KULeuven, Dublin City University, Split Medical Faculty, University of Manchester, University of Oslo, University of Debrecen, European University Madrid). Also an IT firm, specialized in Wiki technology, participated: Gesinn IT. In 2017, the project received funding from the European Union from Horizon 2020, laying the groundwork for the collaborative research project EnTIRE. Information, tools, education and online training will be available on the platform with the aim of fostering good science.

The platform has been developed on the basis of an extensive stakeholder consultation. This created insight into the possible content, look and feel of the platform. One of the suggestions was to keep a positive tone. This means that it is not a platform to call out mistakes and highlight scandals, but to learn from each other and create a positive atmosphere. Moreover, recommendations from the stakeholder consultation showed that researchers would like usable content, such as an oversight of relevant laws, policies, guidelines and tools for practice. Another recommendation was to create a place where users can share their personal dilemmas. The recommendations of the stakeholders have influenced the development of the platform, from the content to the design and tone, with an active role for the Dutch design company Momkai.

The platform contains thematic pages which provide information on good research practices and misconduct and misbehaviours. Next to this, the platform contains a variety of resources, linking to guidelines, cases, educative tools, experts and relevant committees. A discussion platform was created where users can share their problems and others can reply and help. The training tools, which will be available soon, will create a train-the-trainer program to uphold excellent research standards. A unique feature, which is still under development, is the use of semantic media wiki. Just like Wikipedia users can actively contribute to pages and update information. In the future all research ethics and integrity experts can easily share their findings, tools and relevant information in the name of fostering good science.

Impressions from the 6th WCRI

During the first week of June a delegation from the project travelled to Hong Kong to the 6th World Conference on Research Integrity. On Tuesday June 4th the platform was presented during a plenary session by Dr. Ana Marušić, after which it went live! The platform was received enthusiastically by the audience and the conference participants. The Embassy delegation was also present behind an exhibition stand, where the platform was promoted by our team of researchers. Next to this a workshop was organised. Here a diverse group of researchers engaged in a discussion session and got a first look at the platform. All in all, a successful week.

Future Steps

The platform is still under development, and you can also become involved. You can, for instance, add thematic pages on your expertise. These pages are made for researchers who are interested in topics related to research integrity or research ethics, or would like to elaborate their knowledge on a topic. When you are working on an interesting research project you can also add a thematic page on this. You can also add resources, for example, on institutional or national guidelines, cases, experts, committees and educational tools. All content is helpful to guide users and make navigating within the complex field of science a bit easier, and better.

Visit the platform via: www.embassy.science

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PROJECT REPORT

Genome Editing. Ethical Assessment

Genome editing technologies such as CRISPR/Cas9 have been a major topic of scientific research and ethical reflection in the past couple of years. A research project commissioned by TA Swiss has looked into the different ethical position papers on this topic. This short overview will present the context of the research, its methodology and some of the major findings.

Context of the Research

TA Swiss has funded an expert study about the technological consequences of Genome Editing (see: <https://www.ta-swiss.ch/en/projects/biotechnology-medicine/genome-editing/>). In the aftermath of the development of CRISPR/Cas9 technology, the aim of this study was to explore the potentials of different genome editing technologies in human medicine and stockbreeding as well as the ethical, social and legal aspects thereof. The general project was led by Erich Griessler and coordinated by Alexander Lang from the Institute for Higher Studies in Vienna, the ethical part of the project was conducted by Dominik Harrer, Lukas Kaelin and Michael Fuchs from the Institute for Practical Philosophy/Ethics of the Private Catholic University in Linz. The project started in December 2017; the final report was submitted to TA Swiss in April 2019.

Methodological Approach

In order to systematically analyze the ethical debate, the ethical assessments of national ethics councils, academies of sciences and other similar institutions were collected and systematically evaluated. Among the analyzed position papers of the researched institutions were the Nuffield Council, the National Academies of Sciences, Engineering and Medicine (of the United States) and the German Ethics Council among many others similar institutions. In total 14 position papers of different length, scope and analytical depth were analyzed. The shortest encompassed merely two pages (European Group on Ethics), the longest, including appendices, had more than 300 pages (National Academies). Depending on length and intention of the respective position papers either they simply inform a specific audience regarding the state of scientific and medical affairs, or, in addition to this, they discuss ethical positions and also give recommendations for the way forward. The research included all papers published by these renowned ethics councils between 2015 and 2018.

The analysis of these position papers raised the question of the addressee, the used concepts and relevant distinctions. The main focus of the study, however, were the arguments and the recommendations presented in these position papers. A special focus of the study was the repeated call for

moratorium in the debate about genome editing. The collected information was then put in a tabular form and thus the different position papers were made comparable.

Background of the Normative Evaluation of Genetic Intervention

Two differentiations have proven useful in the normative evaluation of genetic interventions. With regard to the type of intervention, germline intervention has to be distinguished from somatic ones. With regard to its purpose, interventions for therapeutic and preventive goals have to be set apart from the ones aiming at enhancement. In view of these differentiations, somatic genetic interventions for therapeutic purposes traditionally have been seen as desirable in principle, given that the ethical and scientific standards of proportionality, potential alternatives, and risk assessment were taken into consideration. Whereas germline intervention and genetic enhancement have widely been considered as unethical in the past – in view of a disadvantageous benefit/risk assessment, but also on categorical ground.

Findings I: Concepts and Differentiations

With regard to the used concepts and differentiations, a significant expansion and further differentiation of the ethical discussion has taken place. The established distinctions between somatic gene therapy and germline intervention as well as between therapy and enhancement have been complemented by the distinction between research and reproductive medicine. There is a general agreement that germline intervention aiming at the therapy or prevention of diseases are irresponsible because of a lack of proper risk assessment. Yet, to use germline intervention for research purposes to test new therapies and better understand the function of the genome is increasingly considered an ethically justified option. Other position papers differentiate between basic research and translational research or clinical studies while pointing out the difficulties to draw a clear line.

Similar arguments apply to the classical distinction between therapy and enhancement. While in general the distinction is seen as bearing normative force, the difficulty of distinguishing the two in particular cases is emphasized. Sometimes questioning of these differentiations serves the purpose of emphasizing general caution in using genome editing; sometimes it is a mere reminder of the fallibility of the established distinctions for normative evaluations.

Especially the lengthy position papers (Nuffield Council and National Academies) discuss the normative aspects of the used concept of “genome editing”. The “editing” metaphor puts genetic interventions in semantic proximity to an editorial change of a text. It thus suggests higher precision than the hitherto used concept of “genetic engineering”. “Precision” is an

important aspect in considering risk and technology impact assessment – as well as “safety”, “efficiency”, and “specificity” of the clinical applications, as many authors conclude.

Findings II: Recommendations

Whereas the different position papers have put forward a wide range of sometimes contradicting recommendations, they agree on a number of aspects. There is a general sense of the difficulty in coming up with clear-cut general recommendations in view of a fast changing scientific field. There is widespread consensus about applying somatic genome editing for curing disease as long as ethical and scientific protocol is followed. The importance of a proper risk assessment is pointed out to better understand unintended modifications.

There is a general agreement that at present there is no justification for germline genome editing for reproductive purposes. Some position papers oppose such intervention on principled grounds; others make it dependent on a range of conditions such as lack of alternatives, no negative consequences, only singular genes treated, available long-term data etc. These lists of requirements are more or less encompassing, yet all position papers agree that many requirements are not fulfilled yet.

Because of novelty of the technology, there is a strong demand to create a regulatory framework that ensures legal certainty. Given that scientific research is increasingly done in international collaboration and due to the world-wide consequences of genome editing, emphasis is put on the need for international regulations. Not at last because of democratic justifications for such regulation, there is a widespread call for a public debate.

Findings III: Moratorium

Calls for a moratorium are found throughout the different position papers. Moratoria can be seen as regulatory instruments, to gain time and to find a consensus in an ideological conflict. These calls for a moratorium might be of implicit or explicit nature; time is needed, the argument goes, to have a public debate, to foster consensus, to better understand genomics, to have national (or global) regulations, and/or to evaluate potential risks. However, as we have found out in our project, it is by no means self-evident what exactly is intended by the various calls for a moratorium. The purpose of the public debate, for example, might be to educate the general public, to lead an open-ended public discussion, to include additional aspects from a diverse public, or to find guidance for the scientific process.

The purpose of a moratorium is sometimes described to clarify open questions – ethical, social, or empirical ones. Sometimes the time gained by a moratorium should be used to clarify the concepts (such as

“embryo” or “germline”). Sometimes the moratorium should be used to develop a clear legal framework. Dependent on their purpose, moratoria might be imagined with a clear expiry date or as open-ended. In some cases, it becomes quite clear that the call for a moratorium is the result of a compromise between a research-friendly liberal fraction of an ethics council and a conservative-principled one.

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CONFERENCE SNEC LAUSANNE

Conference of the Swiss Network of Ethics of Care (SNEC) on the role of patients' relatives in healthcare (Lausanne, 28-29 October 2018)

The Swiss Network of Ethics of Care (SNEC) was founded in 2016 at the initiative of a group of scholars at the Universities of Lausanne and Zurich in order to provide researchers, healthcare professionals and the public at large, both in Switzerland and abroad, with a platform for exchange and collaboration within the field of ethics of care. SNEC organizes international conferences and workshops annually in order to further explore the philosophical and cultural underpinnings of care ethics as well as the challenges for its clinical implementation. The 2018 conference was entitled “What’s the role for patients’ relatives in healthcare? Interdisciplinary perspectives”. It was held jointly at the University of Lausanne (UNIL) and the University Hospital of Lausanne (CHUV) as a way to involve academics as well as clinicians.

Since the 1970s, patient autonomy has been central to healthcare and to medical ethics more generally. The individual patient has turned into a “decision maker” considered as detached and independent from traditional hierarchical family structures. In this context and from the point of view of healthcare professionals, the role of relatives tends to be limited to their intervention in a situation of decisional incapacity of the patient: when the latter is no longer able to decide for herself, relatives are expected to participate in the decision process or even to represent the patient based on substituted judgment and the patient’s best interests. Disagreements tend to occur between relatives and patients, among relatives, and between relatives and healthcare professionals. Whether it is a specific and brief therapeutic intervention or long-term care, understanding the role of relatives is key to understanding and resolving clinical ethics conflicts as well as personal values conflicts.

Professional caregivers often face the following questions: Who is a close relative of the patient? How and to what extent are family members expected to participate in decision making? When are relatives unable to assume this role? How should we handle conflicts of interests between the patient's and the relative's interests? Such issues can also be addressed by using existing approaches, such as shared decision making or advanced care planning. However, it seems appropriate to broaden the analysis from the perspective of ethics of care by clarifying the role and status of relatives.

The objective of the conference was to explore these issues in depth by addressing them through an interdisciplinary perspective, which included contributions from philosophers, healthcare professionals, clinicians, anthropologists and literary scholars. First, the conference aimed to question and clarify the role of relatives based on field experiences of two professional mediators from the Lausanne University Hospital who presented a wide range of testimonials, including complaints, entrusted to them in more than 500 meetings they hold every year with relatives. Besides an overview of the Swiss and international legal concepts of relatives (essentially limiting itself to the role of patient representatives), the conference participants discussed various definitions of what may constitute a "relative", which is not straightforward as it does not merely relate to genetic bonds, physical proximity or legal recognition. This seems particularly pertinent in today's pluralistic and globalized society, where the notion of a relative may even be stretched to include social media relations living on other continents.

In a second step, experienced clinicians and scholars from neonatology, geriatric medicine, psychiatry, and palliative care illustrated the complexity of the theme through various experiences in these medical specialties. A panel composed of a family caregiver, a public health politician, a psychologist and an ethicist discussed how the health care system can provide the appropriate framework and conditions for a thriving relationship of care between the patient and his or her relative. A core ethical question discussed at the conference concerned the interests and rights of relatives: Do they have genuine moral interests and rights toward the health care professionals, in other words: Do health care professionals have the obligation to care for relatives as well, offer supporting discussions, organize psychosocial help for them or assist in reducing conflicts? And, even more controversial: should health care professionals consider the interests of patients' relatives when making treatment decisions about the patient?

The keynote address, delivered by Prof. Inge van Nistelrooij from the University of Humanistic Studies, Utrecht, The Netherlands, explored relational autonomy in care practices and shed particular light on

the role of the partner and the family from a care ethics perspective. As a result, the discussions at the conference sought to go beyond a narrow principle-based ethics understanding of individualistic patient autonomy and patient interest, which often excludes or neglects the relative. Instead, they tried to explore the advantages of an ethics of care perspective, with the specific concepts of "relational autonomy" and "democratic caring" (Joan Tronto) and the "right not to care" (Janet Finch).

The SNEC conference attracted about 40 participants from Switzerland and abroad and presented an opportunity for stimulating reflection as well as network building. Another SNEC conference, as well as workshops, are already planned and anyone interested in the ethics of care and willing to collaborate with the SNEC can informally register on the SNEC website mentioned below in order to receive news about forthcoming events.

Nadja Eggert (Lausanne)
Ralf J. Jox (Lausanne)
Lazare Benaroyo (Lausanne)
Anna Elsner (Zurich)
Roberto Andorno (Zurich)

SNEC website: <https://www.snec.ch>

EVALUATING CLINICAL ETHICS SUPPORT SERVICES (CESS)

Conceptual framework and findings from a Cochrane Review

Introduction

Clinical ethics support services (CESS) have been implemented in many health institutions in Europe. The European Clinical Ethics Network has facilitated exchanges between researchers and practitioners who are involved in a broad range of CESS activities in Europe on a regular basis since 2005 (www.ecenetwork.org). At present, and relevant from an ethical and clinical perspective, a remarkable heterogeneity exists regarding the outcomes chosen to demonstrate the effects of CESS. Our research group, with the support of the German Federal Ministry for Education and Research, has been working on the empirical and normative aspects of evaluating CESS since 2015. In the following, we summarize the findings on the evaluation of CESS designed to support stakeholders regarding ongoing care of one patient. A more detailed report of the findings was published in the July issue of the Cochrane Database of Systematic Reviews [1] and a paper on conceptual frameworks on CESS in BMC Medical Ethics [2].

CESS are heterogeneous and complex interventions

A variety of models of CESS have been described in the literature. It is necessary to identify and explain those elements of CESS, which might contribute to a certain outcome for evaluation research and particularly for experimental studies. This is especially important for so-called “complex interventions,” which encompass several structural and procedural elements possibly contributing to the effectiveness of CESS. CESS dealing with single clinical cases, such as ethics consultation or moral case deliberation, fulfill the criteria of a complex intervention. The different stakeholders (i.e. healthcare professions, patient, and relatives) who might be targets and/or requestors of CESS and the complexity of the communication in the CESS process are among the relevant characteristics.

Conceptual frameworks can serve as a graphic illustration to show the complexity of CESS in a logic model and help one to understand this complex intervention in depth. Our comparative analysis of different approaches of CESS clarifies how CESS models differ regarding their structural and procedural elements and requirements for their implementation in healthcare practice. Furthermore, the ethics consultant's (or facilitator's) role and their required competences differ. The aforementioned differences are relevant for evaluation research, because the choice of outcomes should reflect the goals and mode of action of a specific CESS model.

Findings on effectiveness

All four randomized controlled trials, which fulfilled the inclusion criteria, took place on intensive care units (ICU). Three studies published in five papers originate from the US and one study was conducted in Taiwan. One study showed a significant increase in consensus regarding patient care. One other study investigated satisfaction with care. However, while there was an increase in the intervention, this was not significant statistically. There were heterogeneous results on treatments prior to death (e.g. days on ventilation) and length of stay on the ICU and on general wards. Mortality was not significantly different between the intervention and control group in four studies. In addition, two studies reported that a proportion of patients/relatives and health professionals found CESS stressful. In summary, we cannot be certain about the effects of the CESS interventions included in this systematic review due to scarce evidence and methodological weaknesses, which could introduce bias.

Implications for further research and practice

While experimental studies such as those included in the systematic review serve as a gold standard to determine specific effects, such research is associated with empirical and ethical challenges. The findings on

mortality are a good example in this respect. While mortality is an empirically robust criterion, there are challenges regarding interpreting the findings from an ethical perspective. Exemplarily, if there had been a significant increase in mortality in the intervention group, one ethically relevant question would be what treatment patients would have wanted. However, combining data on patients' will with data on the effects of an intervention on the level of a population is difficult to attain. The use of mixed-methods studies, which combine qualitative and quantitative data from different sources, may be one approach, which meets the ethical and empirical requirements of evaluating CESS.

Any type of evaluation of CESS should consider that CESS are heterogeneous complex interventions. In light of the differing normative assumptions underlying CESS and different clinical contexts and requirements, a broad range of CESS interventions exist. At the same time, it is important to take the existing differences between CESS offers seriously and evaluate CESS in accordance with the underlying goals, theoretical assumptions and processes of the intervention. In order to reach this goal, a programme theory about how the intervention actually works should be developed as a first step of the evaluation research. Moreover, possibly relevant cultural and setting differences should be explored in addition to the potentially negative effects of CESS. Finally, it should be noted that clarification of the goals and structural and procedural elements of specific CESS offers is needed not only for empirical evaluation research. Transparency in this respect is a requirement to be able to communicate potential contributions and limits of CESS in a critical and reflective way.

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Publications

1. Schildmann J, Nadolny S, Haltaufderheide J, Gysels M, Vollmann J, Bausewein C.

Ethical case interventions for adult patients. *Cochrane Database Syst Rev.* 2019 7:CD012636. doi: 0.1002/14651858.CD012636.pub2.

2. Schildmann J, Nadolny S, Haltaufderheide J, Gysels M, Vollmann J, Bausewein C.

Do we understand the intervention? What complex intervention research can teach us for the evaluation of clinical ethics support services (CESS). *BMC Med Ethics.* 2019 20:48. doi: 10.1186/s12910-019-0381-y.

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WORKSHOP OF THE UK-FRANCE GENOMICS AND ETHICS NETWORK:

'Comparative Perspectives on Ethical, Legal and Social Issues of Genomics in Research and Practice'

Big Data Institute, Oxford, 30th September - 1st October 2019

In November 2018, Marie Gaille (SPHERE, Paris) and Ruth Horn (Ethox, Oxford) convened a meeting with a small group of researchers and policy-makers who work in the field of genomics in England and France. The aim of this meeting was to discuss the launch of a network that would bring together researchers from both countries with an interest in the ethical and social issues that arise from new genomic technologies and their clinical application. The meeting was generously hosted by SPHERE, University Paris Denis Diderot. Attending members of the new steering committee of the **UK-FR GENE (Genomics and Ethics Network)** were: *Ruth Horn (The Ethox Centre, WEH, Oxford), Marie Gaille (SPHERE, CNRS- University Paris Diderot), Michael Parker (The Ethox Centre, WEH, Oxford), Mark Bale (Genomics England), Hervé Chneiweiss (CNRS), Jennifer Merchant (University Paris 2 Panthéon-Assas), Anne Cambon-Thomsen (CNRS), Fiona Maleady-Crowe (Genomics England).*

Marie's and Ruth's initiative was prompted by an announcement made by the UK and French Governments in January 2018, to enhance cooperation between Genomics England and the French 'Médecine Génomique 2025' plan. The aim of this cooperation is to deliver a global leading public genomic medicine service. For the first time, two publically funded health care systems will imbed the use of whole genome sequencing into routine patient care; yet each system is based on different values and principles that give rise to different ways of implementing new genomic technologies into clinical practice. The successful achievement of the introduction of genomics into clinical

care requires the development of common approaches, not only to standardisation of the new technologies, but also to ethical standards in research and practice. In order to develop common approaches to good ethical practice, we need a clear understanding of existing debates, regulations and practices, and of the underlying norms in each country.

Therefore, **UK-FR GENE (Genomics and Ethics Network)** provides a platform where British and French researchers and other stakeholders in the field can reflect on ethical and social questions of genomic technologies and their clinical application that emerge in each national context. Its aim is to identify pressing ethical issues in each country and understand their socio-cultural and normative underpinnings. Exploring these issues from a comparative perspective will enable us to shed new light on them and offer potential solutions that are adapted to each context. UK-FR GENE creates an opportunity to develop joint research agendas, and collaborative projects and grant applications that will lead to important outcomes informing ethical standards in the use of genomic technologies and their implementation in clinical practice in the UK and France.

The first of a series of workshops of our network will be held on **30th September and 1st October 2019** at the Big Data Institute, Oxford. This workshop provides an overview of some of the main issues raised by genomics and of the different approaches in each country.

Confirmed speakers are: *Ruth Horn, Marie Gaille, Michael Parker, Mark Bale (Genomics England), Frank Lethimonnier (Inserm), Arnaud de Guerra (French Ministry of Health), Jennifer Merchant (Universite Pantheon-Assas), Anne Cambon-Thomsen (CNRS), Catherine Bourgain (Inserm), Carine Vassy (Iris, Paris), Angeliki Kerasidou (Ethox), Nina Hallowell (Ethox), Edward Dove (Edinburgh Law School), James Buchanan (HERC, NDPH), Adam Hedgecoe (Cardiff University), Angus Clark (Cardiff University), Anneke Lucassen (BSHG, Southampton University), Xavier Guchet (UTC, Compiègne), Alexandra Soulier (Uppsala University).*

In addition, the workshop will be open to all members of the BDI and other teams and departments across the University.

The workshop will focus on the **following themes:**

1. National initiatives in genomic research and medicine and international challenges
2. Collecting, storing and curating genomic data
3. Clinical genomics and data
4. Social contract, trust and privacy
5. Ethical issues in pre-/ neonatal genomics

For further information about our network, please get in touch with us!

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EMPIRICAL BIOETHICS TRAINING COURSE PERU

The first Latin American training course on empirical bioethics at the Universidad Católica de Santa María in Arequipa, Peru¹.

The Centre in Ethics for Medicine (CEM), University of Bristol Medical School, run a two-day training course in empirical bioethics as an introduction for students and professionals who want to learn about integrating empirical and theoretical bioethics research. The course is held annually at the University of Bristol (UoB) and it is organised by Dr. Jonathan Ives, deputy director of the CEM, and involves other staff members, and occasional guest lecturers, with experience in the field of empirical bioethics. The course has an interdisciplinary character and takes a practical approach to supporting participants to think through their methodological concerns about research in bioethics, and at the same time provide them with germane insights into key theoretical frameworks.

On 2nd - 5th July 2019 a special edition of this training course was held at the Medical School of the Universidad Católica de Santa María (UCSM) in the city of Arequipa, Peru¹. Arequipa is a vibrant city located in the second and most important region in Peru¹, named the “White City” for the colour of its traditional colonial buildings, made of a volcanic stone, which adds to its uniqueness. There are four Universities in the City, which presents an opportunity to gather many national and international students and academic staff, which is richly diverse. A delegation of bioethicists attended from Chile, comprising Dr. Ines Donoso Flores, OHiggins University, Dr. Valentina Fajreldin Chuaqui, Dr. Maria Angelica Torres Quintana and Dr. Karin Lagos Bosman, University of Chile. This diversity facilitated a stimulating training course, with participants sharing experience and engaging in an enriching exchange of views and opinions about research in bioethics.

The course was organised and funded by the Office of the Vice-Chancellor for Research and the Presidency of Research Ethics Committee of the UCSM. The CEM, in

¹ Mainetti JA, Perez ML, Los discursos de la bioética en América Latina. In Pessini L, Paul de Barchifontaine C, Lolas F. Perspectivas de la bioética en Iberoamérica. Andreos impresores: 2007, pp. 37-42

collaboration with the Instituto de Ética Clínica Francisco Valles (IECFV), Madrid, designed and directed a special edition of the *Empirical Bioethics – Two Day Training course*
<http://www.bristol.ac.uk/population-health-sciences/centres/ethics/seminars/2019/event-empirical-bioethics-training.html>.

Program sessions were held by Dr. Jonathan Ives, supported by Dr. Emanuele Valenti and Prof. Águeda Muñoz del Carpio Toia.

The course introduced empirical bioethics, its definition and birth (in the European context), and presented an interesting comparison between Europe and contemporary South American bioethics. The development of bioethics in South American countries started under the influence of Northern America (Mainetti, 2007)¹, and the legal frameworks and the first institutions providing assessment for research ethics and health care ethics consultation was strongly influenced by the principles of American bioethics (Lolas, 2014)² (promoted by the training programs of the Fogarty International Center, funded by the National Institute of Health, US). During the 1990's, through the support of the Pan American Health Organization and the engagement of some charismatic bioethicists, structured educational programs in bioethics became available for health care professionals, researchers and progressively for medical students (Lolas, 2010).³

The birth of a first generation of bioethicists promoted a critical reflection about the traditional model of American bioethics and cemented the need to rethink approaches to bioethics in the context of South America, and this permitted the influence of more European approaches to bioethics. Bioethics has not been institutionalised in South American countries to some extent, with the creation of national commissions for bioethics, extended networks for research ethics and health care ethics committees, training programmes for undergraduate and postgraduate medical students and the existence of several associations such as FELAIBE (Latin American Federation of the Institutions in Bioethics) the equivalent of EACME in Europe, or RedBioética a network linked with the UNESCO.

Despite this, South American bioethics today is facing an institutional crisis due to the lack of funds and resources available and perhaps this could be an opportunity for a next generation of South American Bioethicists to achieve independence and develop its

² Lolas Stepke F. Latin American Perspectives. In Ten Have H, Gordjin B, Handbook of Global Bioethics. Springer: Dordrecht. pp. 311-325

³ Lolas Stepke F. Bioethics at the Pan American Health Organization: Origins, development, and challenges. Acta Bioethica, 12: 113-119

own identity. Whilst the role of large funders (such as NIH and WHO) and the contribution of charismatic figures have been essential in promoting and laying the foundations for a Latin American Bioethics, these cannot be taken for granted. Changes in the economic outlook caused by the global financial crisis have forced the Governments to drastically cut health care costs, and this has had a great impact on the efficiency of the health care services. This poses new challenges for the South American bioethics today, which needs to both respond to the loss of quality care and related ethical issues arising, but also to forge its own self-sustainable identity in the face of lack of public funds or the support of external international funders to support education in bioethics.

The conclusion of the workshop discussions with academics and medical students was that Empirical Bioethics has the potential to play a role in promoting a sustainable model of bioethics in South America, focussed on practical and fundable research that could contribute to a bioethics that reflects the diversity of a multi-cultural public who can participate in the research process. Let us hope for further collaboration in the future.

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THE TEACHING OF BIOETHICS FOR HEALTH PROFESSIONALS FROM A TRANSDISCIPLINARY VIEWPOINT⁴

1 Introduction

The present research intends to center the analysis on the problem that exists in the development of the current education of bioethics for the health professionals, within a highly changing world and with the great complexity in the human actions and practices. This results in a complex reality, which demands a pressing conjunction of knowledge, the application of complex methods of thought and transdisciplinary vision.

Carlos Edmundo Maldonado is taken as the theoretical reference, since he has especially worked on the combination of bioethics and transdisciplinarity, both key aspects for the present text. This is without forgetting another series of authors who in one way or another have written about complex thinking, transdisciplinarity, bioethics or health, such as, for example, Morin and Carrizo, among others. Likewise,

the roles played by the ethics committees in the practice of public health are studied in detail, and end up denoting the necessary application of transdisciplinarity in the teaching of bioethics to health professionals. Acquiring knowledge of the world has been imperative for man in modernity. Science in this way "has resorted to methods of empirical and logical verification being relegated and blinded by the lights of reason? Reason, myths and darkness. Contradictorily, the error, the ignorance and the blindness, do not stop, in any scope and with the increase of knowledge "(Morin, 2003: 27). Perhaps, it is necessary to become aware of the problems in the progress of knowledge, related to false perception or incoherence, to seek again the way in which ideas are organized around the object of knowledge. The development of science as it is known up to now, allows an intensive and constant use of knowledge in all areas of society beyond the academic, thus generating the 'knowledge society'. Its purpose is - according to Castells- to improve the relationship between people well and equally, however, inequality among men has increased, the latter being an extremely important aspect in the field of health. With the emergence of the term 'health sciences', the paradigm that conceived health as the sole object of study has been questioned, the current paradigm recognizes the multiple difficulties present in the differences of tools and languages to study it. Thus, health is no longer an object of study but a problem to understand and resolve, it has ceased to be anthropocentric and to become a complex interaction of ecological and biocentric systems, increasing its complexity through the study of complex non-linear systems. Now, when studying health systems, it is essential to consider factors such as

poverty, hunger, pollution, overexploitation and depletion of natural resources, sociopolitical conflicts, economic and financial policies, as well as humanitarian crises and demographic problems. The health sciences have the specificity of working with a problem that demands, from the beginning, with a mental openness considering it an open, in process, unfinished and indeterminate system (Maldonado, 2008: 97).

2 Bioethics from transdisciplinarity

Interdisciplinarity in complex thought -according to Salvador- refers to the transfer of methods from one discipline to another, observing three degrees: application, epistemological and generation of new disciplines. It is understood as an investigative effort between several disciplines. Transdisciplinarity "is or is between, through and beyond the disciplines and having as pillars the following: levels of reality, logic of the third included and the complexity that determines

⁴ Appreciation for the translation to Lic. David Pérez Guerra

the methodology (...)".

Transdisciplinarity -according to Montalvo- goes beyond the limits of the interdisciplinary. Its intention is to overcome the division of knowledge, beyond the contribution of disciplines with different knowledge (multidisciplinarity) and the epistemological exchange and scientific methods of knowledge (interdisciplinarity). In different universities and research centers there are important efforts, linked to reforms in education for the development of transdisciplinary thinking, crucial for the development of an attitude with these characteristics. Pautassi suggests that as not all environments are moral, there may be immoral normativities. The biological organism enables the higher functions of the spirit, the learner can reason, deliberate and make a critical judgment on the moral lived and formulated based on universal ethical principles. Thus, the post-conventional level of Kohlberg's theory is present: to be an ethical subject of his work (moral thought). Ethics, as moral thought, seeks to humanize the meaning of life, to unmask alienating situations by distinguishing "the valid from the current and the correct from the accepted" (Pautassi, 2006: 108). Hence the need to educate to be critical in any situation. Bioethics also integrates a critical analysis of the meaning of the human being as a biological entity, as a socially constructed person. With a clear interest in life, the individual should elaborate on his personal project of existence. In addition to this, "bioethics is concerned about those who lack rationality or suffer from disempowerment, preventing them from being considered as capable of generating a life project" (Kottow, 2010: 167). The recognition of others is essential to establish an ethical dialogue. From this proposal, bioethics could gain a perspective on realities where bioethics does not take note today or does so in a fragmentary and inconstant way, manifesting itself in a weak ethical concern with marginalized populations, the poor, the illegal, the socially excluded only receiving a nonspecific and diluted recognition. Bioethics can contribute to the establishment of a civil ethic proper to societies with autonomous individuals, that is, with the ability to deliberate and participate in the decisions that concern them. The characteristic features and procedures used by bioethics allow being an expression and vehicle of the civil ethics of current societies. Sánchez says that the main functions of bioethics will be new instruments in shaping civil ethics in participatory and deliberative democratic societies, through the following characteristics:

- Rationality
- Dialogue
- Deliberation
- Public transparency
- Individual and social autonomy
- Possibility of everyone's participation (Sánchez (2011: 341).

Regarding the contents of the education programs in Bioethics, they are proposed to include: public health issues for students to think about priority problems of the community. The importance is that in all countries, health systems are subject to criticism. Thus, students must be witnesses of the application of bioethics and not only theoretical concepts. The social and economic changes of Latin American countries not only affect and threaten doctors or health professionals in their moral behavior, there are also scientific and technological changes, as well as social changes. The society that privileges consumption and competition loses values such as solidarity and respect for the dignity of people, generate conflicts and threats to the moral behavior of doctors and health professionals living in this society. Bioethics education will provide knowledge and skills so that professionals can face these challenges in the best way possible. Education by itself is complex, but transdisciplinarity takes up the nature of knowledge. The human being with capacities, should take into account in his education, "the evaluation that implies the conscience of the way in which the changes are taking place" (Montt, 2000: 19). During the First World Congress of Transdisciplinarity, Freitas, Morin and Nicolescu (1994) as representatives of the drafting committee of the 'Charter of Transdisciplinarity', considered it as a set of fundamental principles of the spirit of the community of transdisciplinary, constituting a moral contract that each of the signatories made with itself, outside of any legal or institutional restriction. Education then, was fundamental to this progress, based on the following articles:

Article 9: Transdisciplinarity leads to an open attitude towards myth, religion and towards those who respect these beliefs with a transdisciplinary spirit.

Article 10: There is no privileged cultural place from which one can judge other cultures. The transdisciplinary theory is itself, transcultural.

Article 11: Authentic education cannot privilege abstraction over other forms of knowledge. It must teach to contextualize, to specify and to globalize. Transdisciplinary education reevaluates the role of intuition, of the imaginary, of sensitivity and of the body, in the transmission of knowledge.

3 University, bioethics and transdisciplinarity

Schmidt recognizes the University as something more than a place to research and teach or study and learn or a mere stage of higher education, or a place of exchange (passive and active), information, knowledge, scientific and experiential experiences. Better yet, he considers him a service center for the human resource and developer of human knowledge. The relationship between research and teaching involves the demands of research with an influence on

teaching. While each discipline is taught systematically and according to its own methods, interdisciplinarity helps students to acquire an organic vision of reality and to develop an incessant desire for intellectual progress. The moral implications of each discipline are "considered as an integral part of the teaching of the same discipline; and this so that the entire educational process is oriented, in short, to the integral development of the person" (Schmidt, 2008: 81). Transdisciplinary research that proposes solutions, in the democratic debate of local or national organizations of bioethics and ethics is fundamentally necessary. Deliberations about the dilemmas of social and moral justice that arise when trying to integrate local, global bioethics policies will inevitably generate conflicts and debates, enables "to have ethical concepts and a transdisciplinary research method that keeps clear non-negotiable principles, it will allow the emergence of positive effects where thought and research come together to achieve common good, justice and peace" (Mazzanti, 2010: 163). Education and research are engines of change in science and technology, but not in social and cultural changes, but they can influence the formulation of policies and guidelines of those who work in it. Then, "teachers as a bridge between the present and the future, between illusions and realities, must forge the paths of search for transcendence, knowledge, values and attitudes of students" (Schmidt, 2008: 83).

4 Conclusions

In the complex task of designing and implementing educational models in academic institutions, these institutions must have learning units in humanities. Bioethics should then also be a fundamental part of the formal education and schooling of all young people learning to exercise a profession in society. Global bioethics and (the 'complex thinking' in) transdisciplinarity is knowledge that goes beyond positivism. It must seek from personal, interpersonal, cultural and inter-cultural, institutional and inter-institutional, inter and transdisciplinary forms the search towards "New humanity" (Maldonado, Osorio and Delgado, 2013: 40) A different relationship to the current one of man with biological-cultural systems, since man not only is part of these systems but depends on them for their survival. Of this, there is an urgent and imminent need to think about education for a transdisciplinary bioethics.

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VACANCY EXECUTIVE BOARD SECRETARY EACME

Spread the word please: Vacancy Executive Board Secretary EACME

Our EACME Executive Board Secretary, Angelique Heijnen, will stop at the end of 2020. She has done the job over 20 years.

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- A natural assertive attitude and strong communication, organization and planning skills;
- Excellent verbal and written communication skills in English;
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a.heijnen@maastrichtuniversity.nl

The deadline for applicants to turn in this email:
1st September.

First interviews will be done by Skype and scheduled in October.

NEW EACME MEMBER

Qui est le BEC ?

Le Bureau de l'éthique clinique de la Faculté de Médecine de l'Université de Montréal, constitué de MD spécialistes, MD de famille, une juriste, une éthicienne clinique issue du milieu des sciences humaines, vise à développer et à intégrer l'éthique dans tous les aspects de la culture facultaire.

Que peuvent vous offrir nos programmes ?

Cours d'études supérieures : Microprogramme, Maîtrise professionnelle, Maîtrise de recherche, Doctorat et formation continue. Trois nouveaux cours: deux cours en ligne (dès septembre 2019) et un cours de pratique intensive en éthique clinique.

Quelles sont certaines des forces de notre programme ?

Collaboration interdisciplinaire, interaction avec une unité de consultation en éthique clinique, réflexions éthiques théoriques ancrées dans les réalités de la clinique.

Le Bureau de l'éthique clinique (BEC) de la Faculté de médecine de l'Université de Montréal a récemment rejoint l'EACME. L'équipe du BEC est enthousiaste et motivée à développer des collaborations avec ses partenaires européens. Nous vous présentons dans ce court texte notre équipe, son mandat et un de ses plus récents développements : des cours en ligne en éthique clinique avec des stages intensifs en milieu de soins.

D'abord, l'équipe du BEC est dirigée par le professeur Antoine Payot, néonatalogiste, qui est également à l'origine du développement des Programmes d'enseignement de l'éthique clinique à la Faculté de médecine de l'Université de Montréal. Cette faculté se retrouve en tête de liste en Amérique du Nord pour le

nombre d'admissions en médecine. Elle est celle ayant un des plus vastes éventails de programmes de formation médicale postdoctorale au Canada, avec ses 73 programmes de résidence.

L'équipe du BEC est constituée de médecins spécialistes, d'un omnipraticien, d'une juriste et d'une éthicienne clinique provenant des sciences humaines. Le BEC a comme mandat de développer une vision structurée, cohérente et fédératrice de l'éthique clinique au sein de la communauté facultaire afin qu'elle s'intègre dans la culture quotidienne et dans ses multiples activités. Il s'implique dans les quatre sphères facultaires : l'enseignement, la clinique, la recherche et le partenariat social.

Parmi les activités structurantes du BEC, mentionnons ses programmes de formation en éthique clinique (**Microprogramme, Maîtrise professionnelle, Maîtrise de recherche, Doctorat et formation continue**) qui offrent un arrimage direct de l'enseignement de l'éthique clinique aux réalités de terrain. La plupart des cours sont donnés dans une formule interdisciplinaire, en collaboration avec des intervenants de sciences humaines, des intervenants sociaux, des cliniciens et des patients partenaires au sein d'une unité d'éthique clinique institutionnelle. Les étudiants sont confrontés chaque semaine aux réalités de terrain de la consultation éthique, organisationnelle ainsi qu'au fonctionnement interdisciplinaire.

Un des plus récents projets du BEC a été de développer trois nouveaux cours afin de pouvoir rejoindre un public plus large. Il s'agit de deux cours en ligne et d'un cours de pratique intensive en éthique clinique. Conscient des besoins de formation en région éloignée et dans la francophonie, le BEC a décidé de mettre à la disposition des étudiants un parcours flexible pour les personnes désirant acquérir des compétences et des connaissances dans le domaine, mais qui ne peuvent pas se déplacer chaque semaine pour assister à un cours à l'université.

Tout au long du parcours en ligne de septembre à avril, les étudiants sont initiés à l'éthique clinique dans ses fondements théoriques, mais aussi dans ses enjeux éthiques complexes tels que ceux liés à la transplantation, aux soins à domicile, aux soins de fin de vie, etc. Le cours de pratique intensive lui se déroule sur deux semaines au total ; une semaine avant de débiter le cours en ligne et une autre semaine à la fin du parcours. Ce cours de pratique intensive permet aux étudiants de développer la posture nécessaire au travail en éthique clinique de même que des habiletés concrètes telles que de faciliter des délibérations éthiques ou encore d'effectuer de la médiation en éthique clinique. Ces cours seront offerts sous la forme de cours universitaires ou sous forme de

développement professionnel pour ceux qui ne souhaitent pas s'inscrire comme étudiants ou ne nécessitent pas de diplôme universitaire. Nous accueillerons la première cohorte d'étudiants en septembre 2019. Nous croyons que la modalité en ligne permettra des échanges également avec certains pays francophones d'Europe. Ceci ouvre donc la porte à des échanges interculturels stimulants !

Pour en savoir plus sur le BEC et sur nos programmes d'éthique clinique, vous pouvez consulter le site Internet suivant : <https://www.ethiqueclinique.ca> et nous contacter à ethiqueclinique@umontreal.ca

Au plaisir de vous rencontrer lors des prochaines conférences EACME !

L'équipe du BEC de l'Université de Montréal

Who is the CEB?

The Clinical Ethics Bureau (CEB) of the Faculty of Medicine at the University of Montreal, composed of MD specialists, a family physician, a lawyer, a clinical ethicist from the social sciences and humanities, aims to develop and integrate ethics into all aspects of the faculty culture.

What can our programs offer you?

Graduate studies: Microprogram, Professional Master's, Research Master's, Doctoral and Continuing Education courses, three new courses have been added: two online courses (starting September 2019) and one intensive practice course in clinical ethics.

What are some of the strengths of our program?

Interdisciplinary collaboration, interaction with a clinical ethics consultation unit, theoretical ethical reflections rooted in the realities of the clinic.

The Clinical Ethics Bureau (CEB) of the Faculty of Medicine at the University of Montreal recently joined the EACME. The CEB team is enthusiastic and motivated to develop collaborations with its European partners. In this short text, we present our team, its mandate and one of its most recent developments: online courses in clinical ethics with intensive internships in the healthcare setting.

First, the CEB team is led by Professor Antoine Payot, a neonatologist, who is also responsible for the development of the Clinical Ethics Teaching Programs at the Faculty of Medicine at the University of Montreal. This faculty is at the top of the list in North America for the number of medical admissions. It is the one with one of the widest ranges of postgraduate medical training programs in Canada, with 73 residency programs.

The CEB team consists of medical specialists, a general practitioner, a lawyer and a clinical ethicist from the social sciences and humanities. The CEB's mandate is to develop a structured, coherent and unifying vision of clinical ethics within the faculty community so that it is integrated into the daily culture and its many activities. The CEB is involved in four spheres of the Faculty : teaching, clinical, research and social partnership.

Among the CEB's structuring activities are its clinical ethics training programs (Microprogram, Professional Master's, Master of Research, Doctoral and Continuing Education), which provide a direct link between clinical ethics teaching and clinical realities. Most courses are delivered in an interdisciplinary format, in partnership with social scientists, social workers, clinicians and patient partners within an institutional clinical ethics unit. Every week, students are confronted with the realities of ethical, organizational and interdisciplinary consultation in the field.

One of the CEB's most recent projects has been to develop three new courses. These are two online courses and one in intensive clinical ethics practice. Aware of the training needs in remote regions and in the Francophonie, the CEB has decided to provide students with a flexible pathway for those who wish to acquire skills and knowledge in the field of clinical ethics but who cannot travel each week to attend a university course.

Throughout the online curriculum from September to April, students are introduced to clinical ethics in its theoretical foundations, but also in its complex ethical issues such as those related to transplantation, home care, end-of-life care, etc. The intensive practice course takes place over a total of two weeks; one week before starting the online curriculum and another week at the end of the course. This intensive practice course allows students to develop the posture necessary for work in clinical ethics as well as practical skills such as facilitating ethical deliberations or conducting mediation in clinical ethics. We will welcome the first cohort of students in September 2019. We believe that the online modality will also allow exchanges with some French-speaking countries in Europe. This opens the door to stimulating intercultural exchanges!

To learn more about the CEB and our clinical ethics programs, please visit: <https://www.ethiqueclinique.ca> or contact us at ethiqueclinique@umontreal.ca

We look forward to meeting you at the next EACME conferences!

The University of Montreal's CEB Team

BOOK REVIEW

Un ouvrage remarquable sur la médecine et les soins palliatifs

Kathryn Mannix

With the End in Mind

How to Live and Die Well

London: William Collins, 2018, 359 p.

Kathryn Mannix est une médecin spécialiste de soins palliatifs qui a gravi les échelons au sein du National Health Service britannique. « Au cours des 30 ans de ma carrière, il m'est devenu de plus en plus clair que quelqu'un devait dire à la communauté ce qu'est le mourir (dying) normal. »

Le livre compte six parties pour 36 chapitres ; chacun d'entre eux rapporte l'histoire d'un-e patient-e et de son entourage ; soit en hospice (dédié aux soins palliatifs), soit à domicile suivi-e par une équipe mobile. Large éventail dans les âges : un petit enfant, des adultes jeunes ou mûrs, d'autres très âgés. Ils souffrent de cancer mais aussi de maladies neuro-musculaires dégénératives ou d'insuffisance respiratoire. « J'ai vu dans ma carrière que, quand nous rencontrons les Grandes Questions, nous apportons nos propres idées et attentes (...) Auparavant, c'était une expérience commune d'observer la mort autour de soi, de se familiariser avec les 'séquences' de l'affaiblissement menant à la fin. » Les progrès de la médecine ont changé cela.

« La plupart des gens imaginent que mourir est déchirant et manque toujours de dignité. Ce n'est pas ce que nous observons en soins palliatifs (...) La manière de décliner suit en général un profil relativement uni. Vers la fin le niveau d'énergie est au plus bas, signe que le temps qui reste est très court. » C'est le moment de (se) rassembler, de dire des choses importantes non encore dites. La dernière veille auprès d'un mourant est un moment pour rendre compte, pour penser à ce qui nous relie et comment la séparation changera nos vies.

« Je suis fascinée par l'énigme de la mort : par le changement indicible de vivant à non-vivant ; par le défi d'être honnête tout en étant empathique ; par les moments de commune humanité. » Prendre du recul pour trouver la bonne perspective est un défi. C'est plus facile si la vie et la mort sont approchées avec une attitude de curiosité plutôt que des certitudes.

On relève les récits où le/la patient-e tout comme l'entourage veulent s'épargner mutuellement, se

cachant la gravité de la situation alors que tous en fait savent – arriver finalement à en parler est une délivrance (cela vaut aussi pour les enfants). « La conspiration du silence est si commune, et si tragique. Les anciens attendent la mort et beaucoup cherchent à en parler. Mais ils sont l'objet de rebuffades des jeunes qui ne peuvent le supporter. »

« Les personnes qui approchent de la mort déplacent d'elles-mêmes le centre de leur monde vers les autres. Elles mettent l'accent sur le fait d'aimer leurs proches et cette gentillesse rayonne sur ceux qui sont alentour. » En fait, la plupart d'entre nous, dit l'auteure, feront l'expérience d'une progression surprenante de douceur (unexpectedly gentle) vers la mort. Mannix rappelle ce qu'il importe de pouvoir dire/élaborer, de part et d'autre, avant de se séparer : « Je vous aime », « Je regrette », « Merci », « Je vous pardonne », « Adieu/au revoir ».

A propos des débats actuels sur la fin de vie. Quand un traitement devient-il une interférence qui ne sert qu'à prolonger la mort ? « Avons-nous le droit de choisir quand mettre un terme à notre vie ? [Dans mon expérience,] il n'y a pas de doute que, des deux côtés, ceux qui font campagne [pour ou contre l'euthanasie ou l'assistance au suicide] sont motivés par des éléments de compassion et principe. Pourtant, la discussion, si souvent polarisée, semble avoir peu de rapport avec ce qui est vécu. Beaucoup d'intervenants en soins palliatifs sont exaspérés par les positions tranchées des militants pour l'une ou l'autre vision, alors que nous savons que la réalité n'est ni noire ni blanche mais faite de nuances de gris. »

Le thème de l'immortalité est évoqué dans des termes interpellants. « Les histoires de chaque société incluent des désirs d'immortalité qui presque toujours ont une issue funeste. Ou bien les immortels sont condamnés à la solitude, ou ils finissent par sacrifier leur immortalité pour vivre une vie de mortels... La sagesse des civilisations reconnaît l'immortalité comme une coupe empoisonnée, et la mort comme une composante nécessaire et même bienvenue de la condition humaine ; une limite qui rend le temps et les relations entre nous infiniment précieux. »

L'ouvrage a une vraie valeur pédagogique, fourmillant d'utiles notations et conseils. Une remarque : tous les professionnels décrits sont compétents, toujours adéquats dans leur travail. Portant sur toute une carrière dans le monde réel, cette perfection surprend un peu... Exquise courtoisie britannique ? With the End in Mind apporte une contribution importante aux débats actuels sur la mort et le mourir, dans un système de santé critiqué pour son « maximalisme » et son attention insuffisante à ce qui se passe - ou pas - entre soignés et soignants. Il est susceptible de susciter des vocations pour les soins palliatifs. Noter encore que ce

livre a été traduit en italien, espagnol et néerlandais, mais pas en français à ce stade.

Dr Jean Martin

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DEADLINE NEXT NEWSLETTER

The deadline for the third edition of 2019:

November 15, 2019

If you wish to promote your event, or to inform your EACME-colleagues about the results of your work, descriptions of projects, book reviews etc. Any good ideas for the upcoming edition?

Don't hesitate to contact our editor Giles Birchley:

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