EACME Newsletter

EUROPEAN ASSOCIATION OF CENTRES OF MEDICAL ETHICS

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Dear EACME colleagues and friends,

With Christmas and the end of the year approaching fast, I hope you can take some time to reminisce about what 2022 has brought you personally and professionally.

Professionally, it was great to see so many of you – finally in person again – at the EACME conference in Varese and to continue the 'dialogue to bridge the gaps in bioethics'. During the conference, it once more became apparent that the dialogue in and on bioethics is not limited to a dialogue in English, but can include a variety of languages spoken in our EACME community. The EACME Bureau and Board think that it is important to open the dialogue also to those centers, who primarily work in other languages and in which they feel more confident.

We therefore encourage members to promote their research as well as webinars and conferences, which are held in other languages than English, in the EACME News and the EACME Newsletter. Through this, we hope that the dialogue gets even more diverse and engaging for all EACME members.

In this edition of the newsletter, we are happy to present you a variety of articles, presenting among others latest research on how the COVID-19 pandemic has changed the ways doctors make end-of-life decisions, an account on why research integrity matters and a webinar report on the topic of "MPOX, Bioethics, and the LGBTQI+ Community". In addition, we started a new interview series with chair holders in medical ethics in EACME members institutes to present the focus of and vision for their chair as well as to inform about new developments and projects.

We furthermore received a contribution about the team participation in this year's EACME Conference by the Centre for Biomedical Ethics and Law, KU Leuven, which might hopefully inspire other member centers for the next conference.

But for now, I wish you an enjoyable end of the year and happy holidays.

Warmest wishes,
Caroline Brall

NEWS FROM THE EACME BUREAU

Dear EACME members, dear friends and colleagues,

We hope this finds you all well and healthy, and you look forward to a quiet festive season with your friends and family.

To close this year and discuss the past year as well as the years to come, the members of the EACME Bureau met at the beginning of December in Munich. Looking back at this year, we all agreed that it has been a good and productive year for the EACME, and that many new opportunities were created on which we can build in the future.

We are very grateful to have Angelique back to support our administrative work. As Federico said at the annual conference, she is the “rock” of the EACME, and helps us build a strong and solid structure. We would also like to thank Pawel who joined the Bureau as a new member, as well as our new and re-elected Board members Kristine Baroe (Bergen) and Sebastian Wäscher (Zurich).

Our annual conference, hosted by Mario Picozzi and his team in Varese, the new network for Early Career Bioethicists, initiated by Richard Huxtable and Danny O’Connor from Bristol, and the new members from Munich and Lund, are an expression of the strength of our community built on exchange and dialogue with colleagues from different countries and disciplines.

We hope to continue attracting new centres, and continue to be attractive for existing centres, among others, through the exchange and networking opportunities the EACME offers. One example to make use of these networks are our EACME Visiting Scholarships and the Collaboration Awards to which we would like to draw your attention again. Please spread the word and invite your colleagues, particularly those at the beginning of their career, to apply for these opportunities!

For more details and information about our activities this past year, please look out for the End-of-the-Year letter which will be sent via Email to everyone.

Wishing you a joyful Holiday Season and best wishes for a healthy, happy, and peaceful 2023,

Ruth, on behalf also of Bert, Federico, Pawel and Angelique

Doctors Now More Likely to Make Patients DNACPR- New Research Shows

Dr Benjamin Chang
Graduate, MA Bioethics & Medical Law
Centre for Bioethics & Emerging Technologies (CBET), St Mary's University, Twickenham, London

The COVID-19 pandemic has transformed many aspects of medical practice, including, and perhaps especially, end-of-life care. In a new piece of research published in the Journal of Medical Ethics (Chang & Matthews, 2022), we investigate how the COVID-19 pandemic is changing the ways doctors in the NHS make end-of-life decisions. The research was conducted by questionnaire sent to 231 NHS doctors between May and August 2021, during which COVID-19 hospital cases were relatively low. There were three areas that we focussed on: DNACPR decisions, treatment escalation, and views on medically-assisted dying.

DNACPR Decisions

At the start of the UK COVID-19 epidemic, there was an increased urgency amongst clinicians to make DNACPR decisions for their patients, in part due to the increase in cardiac arrests linked to COVID-19 infections (*Hayek et al.* 2020). However, a year into the pandemic, the Care Quality Commission published a report which highlighted several areas of concern about DNACPR decision-making during the pandemic (CQC, 2021). It found that 30% of patients surveyed with DNACPRs were not aware that a DNACPR had been put in place, and it criticised the use of "blanket" DNACPRs across over a hundred adult social care settings.

In light of these developments and controversies, we sought to investigate if there had been a significant effect of the pandemic on DNACPR decision-making.

Our results showed that over half of participants (54%) reported that they are now making more patients DNACPR than pre-pandemic, and this was due, at least in part, to an increased focus on factors including patient age, clinical frailty scores, and resource limitations. We suggest that this may indicate a subtle shift amongst some clinicians, away from the patient-centred ethic mandated by the General Medical Council (GMC, 2010), and toward a more utilitarian ethic as proposed by the British Medical Association near the start of the pandemic in their "COVID-19-Ethical Issues" guidance (BMA, 2021).

Treatment Escalation

At the beginning of the pandemic, there was widespread concern over the UK's ITU capacity to cope with the unprecedented numbers of critically unwell patients. In response, the National Institute for Health and Clinical Excellence published guidelines stating that admission to ITU should only be considered if a patient is likely to recover (NICE, 2021). There was also increased focus on early palliative care intervention, with several influential medical journals publishing articles guiding clinicians on early palliative care for patients with severe COVID infection (*Radbruch et al*., 2020; Ting et al., 2020). These led us to investigate if the pandemic has caused clinicians to raise their thresholds for referring patients to ITU, and/or lower their thresholds for palliation.

Our research found that the largest proportion of participants had not changed their thresholds for escalating patients to ITU or palliating patients since the start of the pandemic. However, a substantial minority did report that they now had a higher threshold for escalating to ITU (26%) and a lower threshold for palliation (23%). When asked for the reasons for this, several participants cited formative experiences during the peaks of the pandemic that educated them on the burdens and limitations of ITU care, and/or the value and appropriateness of early palliation.

Medically-Assisted Dying

In 2019 and 2020, the British Medical Association, Royal College of Physicians and Royal College of GPs polled their members' views on the legalisation of medically-assisted dying. Significantly, all three surveys were carried out before the start of the pandemic. There is little data available on how the experiences of the pandemic have changed clinicians' views on the legalisation of medically-assisted dying, if at all. This is of clear contemporary relevance in light of Baroness Meacher's Assisted Dying Bill which is currently in the parliamentary committee stage.

Our research found that pre-pandemic, the largest proportion of participants were opposed both to the legalisation of euthanasia (47%) and physician-assisted suicide (51%). These results were similar to the Royal College of Physicians (2019) survey. We then found that since the start of the pandemic, there has not been a statistically significant change in views of clinicians on the legalisation of euthanasia or physician-assisted suicide.

Conclusion

In summary, our research found that over half of clinicians surveyed reported that they are now making more patients DNACPR than pre-pandemic, and a sizeable minority now have a higher threshold for referring to ITU, and lower threshold for palliation. Views on medically-assisted dying appear to have stayed the same.

What is yet to be determined is whether these changes will now stay the same indefinitely, revert back to pre-pandemic practices, or evolve even further. Thus our paper is only the beginning of the important exploration into how COVID is changing the ways doctors make end-of-life decisions.

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Why research integrity matters

Reflections on the symposium 'how to foster responsible research practices' and the valedictorian lecture 'Why Research Integrity matters' by prof dr LM Bouter

Written by Joeri Tijdink

Introduction

On Friday 23 September 2022, the Netherlands Research Integrity Network organised a symposium 'How to foster responsible research practices' prior to the valedictorian Lecture entitled Why research integrity matters by Prof Dr. Lex Bouter. Lex Bouter is a professor in Methodology and Integrity at the Vrije Universiteit Amsterdam in the Netherlands and has dedicated the last 10 years of his career to research integrity and how to foster responsible research practices in academia. In this short summary, we briefly reflect on the symposium that was organised before the lecture, the lecture itself and the lessons we can learn from his lecture.

The symposium

The symposium was divided into three parts that focused on three important stakeholders that should be responsible for research integrity.

First, three speakers (Malcolm Macleod, Gowri Gopalakrishna and Tamarinde Haven) talked about what institutes can do to foster responsible research practices. They highlighted the important role of research culture and how culture can shape and influence the behaviour of researchers. Thereafter, the results of the National Survey on Research Integrity were discussed and showcased how important it is to know what are the most frequent questionable research practices to determine prevention and intervention strategies. It also highlighted the role of supervision that was discussed in more detail by the third speaker. Responsible supervision can improve responsible research practices.

The next three speakers (Maura Hiney, Joeri Tijdink and Noémie Aubert Bonn) talked about the important role funders have in incentivizing researchers towards responsible research practices. Funders have a responsibility towards the quality of the research they fund. They may not be aware of the financial dependency researchers have towards funders. This is an important responsibility that should be handled with care by funders. This dependency is partially due to the hypercompetitive funding schemes with low percentages of granted funding applications. This comes with (un)wanted consequences that funders should be aware of. For example how team science and collaborative research can be valued and assured by using a framework developed by the Health Research Board in Ireland. Furthermore, the results of the SOPs4RI-project were discussed. They created a toolbox with tools that funders can use in order to improve their research integrity standards and demand improvement in the institutes and researchers they fund. Finally, the important role of research assessment was discussed and how they shape research behaviour and (responsible) research practices.

The symposium was concluded with three speakers (Sabine Kleinert, Mario Malicki and Serge Horbach) that discussed the role publishers and journals can play to strengthen research integrity. Not only they are key stakeholders that decide what gets published and what not, they are also responsible for requirements researchers should meet when they want to publish in journals. Like funders, they can demand more than they think. Not only through thorough peer review processes, but also through improving transparency in the peer review process and monitoring the research integrity standards a journal wants to comply with.

The lecture

The day was concluded with the valedictorian lecture 'Why research integrity matters'. In this lecture, Lex Bouter took us on a journey through a plethora of initiatives that are currently shaping the research on research integrity landscape.

He started with a short overview of reasons why research integrity matters. He started with focusing on how trust is essential for scholarly work. When scholars cannot trust each other, collaboration and building on earlier findings becomes impossible. The same holds true for research-based interventions designed to benefit the individual, society or the natural environment. The trustworthiness of research findings is threatened when researchers don't do their utmost best to get it right and engage in questionable research practices or worse. By adopting open science practices, research becomes transparent and accountable. Only then it's possible to verify whether trust in research findings is justified. He used the same structure as the symposium. First, he pictured what research institutes can do, after that he showed what funders and journals can do to foster research integrity.

In the lecture first the magnitude of the issue was illustrated with the results of the Netherlands' National Survey on Research Integrity. Next, he took us further into the risk factors why researchers regularly engage in behaviour that harms the validity and trustworthiness of their work. What is good for the quality and reliability of research is not always good for a scholarly career. Navigating this dilemma depends on how virtuous the researcher at issue is, but also on the local research climate and the perverse incentives in way the research system functions.

As a follow up, Lex Bouter discussed what the main drivers of research misconduct and questionable research practices are and what research institutes, funding agencies and scholarly journals can do to foster research integrity. A strong argument will be made for open data, open methods and open peer review. Additionally, an urgent plea was formulated to reform the way researchers are assessed for grant applications and career steps. This neatly fits into the current (local) initiatives that are being organised and developed to change the current assessment criteria. Although change goes slow, numerous initiatives are currently shaping the reform of these assessments.

The full text of the lecture can be found here: https://www.nrin.nl/docman/how-to-foster-rrp-s/122-lex-bouter-afscheidsrede/file

What is next?

Prof. Dr. Lex Bouter certainly played an impressive role in putting research integrity on everyone's agenda on a national and international level. The research community needs to continue this important work and take the next steps and follow suit to further the work on research integrity and expand the field of metaresearch by research institutes, funders and journals. It is without a doubt that research integrity is essential to maintain and improve the quality of research results and consequently gain trust in research. Now it is time to implement the initiatives and spread the word towards other academic communities and disciplines.

EACME PRIZE WINNERS

Vardev Vordathep from Edinburgh University won the Paul Schotsmans Prize for talented scholars, Bianca Jansky (Institute of Ethics, History and Theory of Medicine Ludwig-Maximilians-University Munich) won the Visitor Scholarship Exchange Programme Prize. And finally, Dr. Anna-Henrikje Seidlein (Institut für Ethik und Geschichte der Medizin , University of Greifswald, Germany), Prof. Rouven Porz (Medical Ethics, Insel Gruppe Bern/ Swiss Academy of Medical Sciences, Bern, Switzerland), Marie-Christine Fritzsche (Institute of History and Ethics of Medicine, TUM School of Medicine, Technical University of Munich, Germany) and further applicant Prof. Helen Kohlen won the Collaboration Award. Congratulations on winning these awards!

Interested in applying for these prizes? See our EACME website: **www.eacmeweb.com**

CHAIR HOLDERS IN MEDICAL ETHICS: THE EACME INTERVIEW SERIES

The Chair of Clinical Ethics Support & Quality of Care (Amsterdam UMC – VU University)

Prof.dr. Bert Molewijk, congratulations on receiving the newly established Chair of Clinical Ethics Support & Quality of Care!
To get some insights into the background, nature and mission of this chair, we would like to ask you some questions:

1. When was the chair founded, in which university infrastructure, what type of chair is

it and what kind of research group is connected to the chair?

The full professor chair (full-time) was founded the first of December 2019, embedded within the department of Ethics, Law and Humanities at the Medical Faculty of Amsterdam UMC and the Free University (VU). The inaugural lecture was on the 10th of November 2021 at the VU university in Amsterdam (twice postponed due to Covid). The chair is embedded within the section Ethics Support & Research Integrity which consists of around 25 colleagues (including researchers, trainers/lecturers, and ethics support staff).

2. What was the reason for establishing it? In which way does the focus of the Chair of Clinical Ethics Support & Quality of Care differ from existing Chairs in Medical Ethics?

The chair is the result of almost 2 decades of work of many colleagues within the domain of Clinical Ethics Support (e.g. Moral Case Deliberation). The chair is both an expression of what has been established and the intention of further strengthening research, training, teaching and innovation in Clinical Ethics Support. There are many chairs in Ethics of Clinical Ethics, yet this is the only chair of Clinical Ethics Support, as far as I know. The chair has three foci points. It focuses on the analyses and recognition of the ethical dimension of all kinds of practices (also beyond the domain of clinical contexts such as prisons and the armed forces). Second, it studies how to support those practices in dealing with the ethical dimension. Third, the chair fosters and monitors the contribution of Ethics Support to the improvement of these practices (e.g. Quality of Care). It is important that Clinical Ethics Support is recognized as a specific subdiscipline of (Clinical) Ethics since it goes beyond the theoretical, empirical and normative study of specific ethics topics. It is a truly interdisciplinary chair (e.g. social sciences, implementation sciences, education sciences, organizational sciences).

3. On which areas and topics are you focusing on in research and teaching? What are some of your current projects? Do you also cooperate with other EACME centers?

The chair has a special assignment. It focuses on three larger topics.

- **Innovation**. This concerns CES methods, instruments/tools, blended learning within CES, CES for and with patients, family & parents.
- **Implementation**. This is about the embeddedness of CES within: care and daily work processes, the organization of care and work, leadership and decision-making.
- **Quality**. This focuses on elaborating on and fostering the theoretical, methodological & normative quality of CES itself on the one hand. On the other hand, it focuses how CES can contribute to the quality of care, self-care, cooperation, conflict management, moral resilience, and the organization as a whole.

Examples of projects with other EACME centers: Together with the Centre of Medical Ethics in Oslo we study whether regular Moral Case Deliberation sessions change specific normative attitudes of MCD participants and whether it contributes to better dealing with disagreement in teams. In Amsterdam UMC, and also with researchers from Leiden University and Stockholm, we study what good participation of patients, family members and parents in Clinical Ethics Support entails. A recent project in Amsterdam UMC focuses on the question whether action research with moral dialogues about appropriate and inappropriate behavior, can contribute to a safer work- and learning climate.

4. Are you offering any activities, e.g. seminars, workshops, webinars, lecture series

etc.? On which topics and for which target groups? Are you hosting visiting researchers?

Our Ethics Support team is organizing or contributing to many local, regional, national and international activities. Examples are (online) trainings of Moral Case Deliberation facilitators (including train-the-trainers), masterclasses of (developing) Ethics Support tools, workshops on the moral inquiry into emotions, webinars using a dilemma game, webinars on quality of ethics support, conferences on moral distress and moral resilience. Furthermore, specific thematic activities which focus on an ethics topic (e.g. covid vaccination, ethical challenges around loyalty for human resource advisers, fair distribution of beds).

5. What is your vision for the future of the discipline of Clinical Ethics Support?

In the near future, we will work on further developing national and international trainings for Ethics Support Staff in different practices/domains, together with our national and international colleagues. The same applies for training researchers in Clinical Ethics Support. With respect to research, theoretical and methodological research is needed about the normativity of and within (various forms/structures of) Clinical Ethics Support. Finally, research is needed how insights and lessons-learned of specific Ethics Support activities can contribute to the learning processes of other teams and the whole organization (e.g. contributing to moral resilience and organizational morisprudence). For example, by creating and implementing thematic Ethics Support Tools.

Webinar Summary

Forum on Global Health Ethics Webinar Report

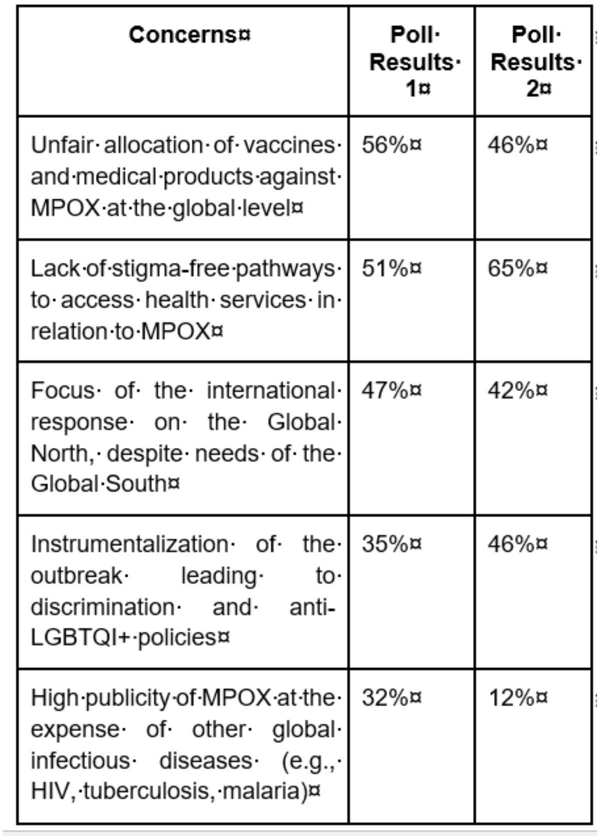
MPOX, Bioethics, and the LGBTQI+ Community

By Dustin Duc Duong and Jan Schwarz

Introduction

In November 2022, the Forum for Global Health Ethics held an online event to discuss LGBTQI+ stigmatization, the broader issues of health inequality, and bioethics in the wake of the monkeypox (MPOX) outbreak. The forum is an outreach project organized by the Institute of Biomedical Ethics and History of Medicine at the University of Zurich (a World Health Organization Collaborating Centre for Bioethics). The Forum for Global Health Ethics and the Swiss Medical Weekly jointly organize a webinar series. The webinar on MPOX gathered a panel of experts, including researchers and policy advisors, to provide a range of different perspectives on the key ethical issues at stake in relation to LGBTQI+ health. Beyond the direct impacts of MPOX on the LGBTQI+ community, the speakers each presented a main concern of the global health response to epidemics, relating to logistical and coordination challenges as well as questions around discrimination and health communication more generally. These key issues touched upon stigmatization, historic distrust within marginalized communities, and, normatively, how actors should contribute to the policy response alongside communities and authorities.

The webinar was hosted by **Nikola Biller-Andorno** and **Tania Manríquez Roa** (University of Zurich, Switzerland). The international experts were Cleiton Euzébio de Lima (Joint United Nations Programme on HIV/AIDS), Julian März (University of Zurich, Switzerland), Stephen Molldrem (University of Texas Medical Branch, United States), and Carla Saenz (Pan-American Health Organization, PAHO). The event was attended by 77 participants, who were asked before and after the speakers' presentations for their opinions on the main concerns of the global health response to the MPOX outbreak. The results can be seen below.



Concerns	Poll Results 1	Poll Results 2
Unfair allocation of vaccines and medical products against MPOX at the global level	56%	46%
Lack of stigma-free pathways to access health services in relation to MPOX	51%	65%
Focus of the international response on the Global North, despite needs of the Global South	47%	42%
Instrumentalization of the outbreak leading to discrimination and anti-LGBTQI+ policies	35%	46%
High publicity of MPOX at the expense of other global infectious diseases (e.g., HIV, tuberculosis, malaria)	32%	12%

The following is a summary of some of the key topics of discussion at the forum.

Current situation of the MPOX outbreak and inequalities

As Cleiton Euzébio de Lima underlined MPOX-V has had a huge influence on the current health situation. There are more than 77,000 confirmed cases and 36 deaths reported regarding MPOX in 109 countries (accessed Oct 27, 2022). As Julian März stated, the most affected countries are the United States of America followed by Brazil, Spain, United Kingdom, France, Germany, Columbia, Peru and Mexico. In the earlier stages of the outbreak, the worldwide focus on MPOX was mainly on the WHO Europe region, but has now shifted to the WHO Americas region. Although, as Cleiton Euzébio de Lima highlighted, MPOX is considered to be a mild to moderate disease compared to COVID-19, it has a hospitalization rate of around 5 to 10%. Regardless of the pure number of cases, we should also thematize the loss of income for isolated patients and the discrimination and stigma regarding the MPOX infection. As seen in figure 1, a higher proportion of cases were recorded in the Region of the Americas relative to the number of cases recorded in the European Region.

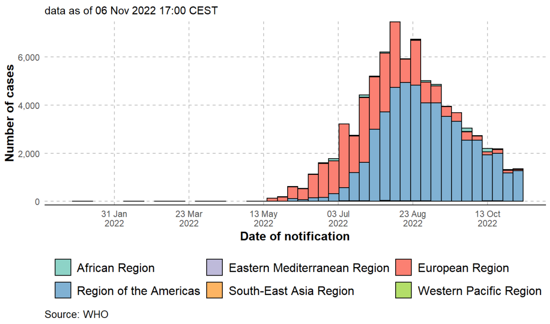


Fig. 1. WHO, Global MPOX epidemic curve by region, accessed November 6, 2022, WHO data, https://worldhealthorg.shinyapps.io/mpx_global/

If we look at the people, who have been diagnosed with MPX and gave information about their sexual orientation, over 87% identified themselves as gay, bisexual and other men who have sex with men (MSM). Additionally, the most commonly reported exposure was in a party setting with sexual contact (approximately 43% of the reported exposure settings). Added to this, we have a high rate of co-infections (approx. 49%) with the Human Immunodeficiency Virus (HIV). Cleiton Euzébio de Lima highlighted this point: a worse outcome is expected if a person has an untreated HIV infection and is MPX-V positive. As Stephen Molldrem suggested, existing disparities regarding ethnicity play a role in the chances that people have in having a HIV diagnosis. He explained that these disparities also occur in MPOX diagnosis. In parallel, he recognized a huge change in the infected patients' ethnicity for the US. In addition to the differences in infections Stephen Molldrem underlined that in October 2022 almost 50% of the MPOX infections occurred in African Americans, but regarding vaccination African Americans only make up 12%. This difference does not only raise the question, why African Americans and black people are less vaccinated than other ethnicities, although they are more often infected, this gap could also be dangerous for the goal to decrease the course of infection.

Inequities exist both at the national level, along the lines of ethnicity and sexuality (according to CDC data presented by Stephen Molldrem, African Americans and Latinos are overrepresented in the proportion of new MPOX cases), as well as the global level, with regards to focus on the Global North despite the needs of the Global South (MPOX was endemic in Africa before the global outbreak). Stephen Molldrem further highlighted that these inequities already existed prior to the outbreak of MPOX, but are further exacerbated and exposed due to the direct consequences on health outcomes and discrimination, entangled with concerns at the policy-response level.

Given these circumstances, Stephen Molldrem reiterated the need to evaluate and modify the existing health care strategies in response to MPOX.

Lessons from the past and the importance of patient experiences

During the webinar, Cleiton Euzébio de Lima especially focused on lessons from the HIV/AIDS response, given his role as Senior Adviser of the Civil Society Networking at UNAIDS. He makes clear that existing prejudices and stigma regarding the LGBTQI+ Community members are impacting the patients in multiple ways. For example, stigma can force people with symptoms to hide their signs of illness instead of visiting a doctor and get medical advice. The stricter the rules and laws for example against homosexual intercourse, the more likely a patient is going to hide their symptoms. This delays the access to testing and health care directly. Moreover, existing stigma can slow down the public health authorities in their actions against MPOX. Therefore, Cleiton Euzébio de Lima suggests a human right approach to support policy makers in creating laws and policies, which empower and protect patients, especially of vulnerable communities, instead of harming them. To create such policies we have to follow some greater “rules”. In line with this, Carla Saenz states that there are some points of consensus on which the international community have to agree. On the one hand the public health authorities have to protect and promote the health of the population that is currently primarily affected, on the other hand those authorities have the duty to ensure that their actions does not intensify the already existing stigma. However the policy makers should also respect the diverse sexual practices, gender orientations and identities. Although the difficulty to cover all aims to their full extent it is not ethically correct to remain “silent”. It is important to act up even if the state criminalizes homosexual intercourse. To ensure for example that the planned actions do not intensify existing stigmas, Cleiton Euzébio de Lima says that policy makers should involve local communities (e.g. LGTBQI+). In general, the creation of communication guidelines should not take place from the top down. Instead of this, affected persons should gain the opportunity to influence the process of making policies. Organizations like the WHO should firstly gain experiences and views from the local communities to let them slip in the creation of discrimination-free policies. To gain such important insights in the patients' life, emotions and thoughts during the MPOX outbreak and their infection, Julian März introduced the DIPEx ("Database of Individual Patients´ Experiences") project. The DIPEx Methodology is an internationally-vetted method for rigorously and systematically eliciting, analyzing, and disseminating maximally heterogeneous health and healthcare experiences. It is based on the pioneering work of the Health Experiences Research Group (HERG) in the Nuffield Department of Primary Care Health Sciences at University of Oxford. During the interviews Julian März is collecting personal characteristics (age, gender, socioeconomic background, racial and ethnic background, geography) and illness characteristics (severity, types of symptoms, treatments). Patients' experiences are crucial in shaping health care responses, so that these policies can improve the current health care regarding MPOX. Needs or insights on negative health care situations can be collected using DIPEx. One greater aim of this project is not only to humanize the MPOX as disease and the patients, but also to prevent stigma and discrimination. Starting with a pilot study (n = 25 - 40) in nine different countries, Julian März and his colleagues try to get an overview about the patient's view on the MPOX outbreak.

Ethical challenges in policy-making

A central point of discussion was also how bioethics could and should be integrated into policy-making in response to outbreaks. Julian März highlighted two major themes of the WHO Expert Group on Monkeypox & Ethics, firstly ethical considerations regarding health communication (naming, language issues, ethical issues to collection and publication of patient experiences, adaptation of health communication to social contexts and the experiences of patients and medical professionals), and secondly access to healthcare (stigma-free pathways to vaccination, diagnostics and treatment). The inequities mentioned above, at the community and international levels, therefore necessitate the integration of ethics in both research and policy-making stages of the response to the MPOX outbreak as well as future health issues. Stephen Molldrem sees the disparities along the lines of ethnicity, sexual orientation, and HIV status as a further manifestation of pre-existing issues in the context of the US public health system. These health disparities, caused by an underfunded health system and distrust due to historic neglect, thus forming a bleak set of "MPOX futures" that might come if we do not proactively learn from past and present outbreaks.

How, then, may we integrate the ethical sphere into an area dominated by medical and legal discourse?

Carla Saenz underlined the duty of different actors, from public health authorities to communities, to take up responsibilities to ensure that inequities and discriminatory practices are not exacerbated by the health response. Collaboration, the objective for improved policy responses, can only take place if there is a building and fostering of trust.

Communicating ethically, for example, is a moral duty that should be undertaken by providing a space for public health ethics vocabulary that is distinct from legal and medical language, but is nevertheless a necessary element of protecting the health of populations at risk. In the case of contact tracing, the challenges related to the fear of misuse of data (such as health authorities sharing medical data with immigration officials) must be addressed capturing moral obligations beyond the legal framework, clarifying our obligations to each other, and achieving coordination through identifying responsibilities and taking up responsibilities for trust-building.

In short, we start to address the layers of stigmatization, discrimination, and health inequalities by taking seriously the need to normatively consider ethical “oughts” and “shoulds”, capturing the full richness and spectrum of the moral vocabulary beyond the legal framework.

Q&A and conclusion

The discussion and Q&A that followed echoed the concerns presented by the expert panel:

- How do we deal with a challenging legal environment, as is the case in countries where homosexuality is criminalized? Access is important and possible, but contact and working with communities or allies is the best approach to build responses that do not cause further harm to already vulnerable communities.
- Quotidian forms of discrimination require outreach in an appropriate way that deals with the needs of at-risk communities. Instrumentalization of outbreaks must be avoided. In the case of Covid-19, raids were conducted on the homes of LGBT people in Uganda, using legalistic and health justifications of pandemic management policies. There are lessons regarding the formulation and implementation of health responses, highlighting the need for a broader consideration of vulnerable communities in times of health emergencies.
- Trust and collaboration must be fostered, keeping in mind ethical guidelines even in technical discussions (see, for example, the WHO Ethics Guidelines on Public Health Surveillance with regards to contact tracing and medical data).
- Each actor at various levels has a responsibility to address the challenges to the general welfare and society. Identifying and taking up these responsibilities is the task of not only researchers, civil society actors, and public health authorities, but also experts, communicators, and policy-makers.

Although it is important not to equate the epidemiologies and experiences of different outbreaks, whether it is HIV, COVID-19, or MPOX, at each instance there is an opportunity and need to learn from errors and mishandling in terms of communication, policy formulation, and discourse. Vaccine equity and equal access to health services, mentioned by Stephen Molldrem for example, should be central to the discussion, as well as the involvement of vulnerable communities in responses to outbreaks, as Carla Saenz and Cleiton Euzébio de Lima highlighted. That we acknowledge the possibilities for further research and discussion on these lessons is vital for moving forward and confronting bleak future scenarios.

The Empirical Bioethics Summer School: A new European training collaboration

Michael Dunn

(On behalf of the organisers of the Summer School: Bert Molewijk, Jan Schildmann and Jonathan Ives)

June 2022 saw the arrival of the inaugural Empirical Bioethics Summer School. Generously funded by the first EACME Collaboration Prize and an award from the VU Vereniging, the Summer School aimed to bring junior scholars from all over Europe (and beyond) together. Our plan was to trigger learning, debate and deliberation about the theory, methodology and methods of empirical bioethics – over 3 intense days in the beautiful city of Amsterdam.

The Summer School was the brainchild of four EACME centres in the UK, Netherlands and Germany. Devised and co-ordinated by Bert Molewijk, Jan Schildmann, Jonathan Ives and Michael Dunn, 25 participants from 17 countries across 4 continents were chosen and were able to draw on the expertise of a number of senior figures in European social science, philosophy and bioethics: Suzanne Metselaar, Veerle Provoost, Fijgje de Boer, Rob Compaijen and Sabine Salloch. We are grateful to our co-teachers for so generously giving up their time to contribute and support this event.

The Summer School started out on the first day under the summer sunshine and with an orientation into the broad landscape of empirical bioethics. Participants considered what this methodological sub-field consists in, how it has developed, and the wide-ranging approaches that have evolved to put it into practice.

In the afternoon, a thread that continued across the 3 days was established. Participants spent time in small group discussions sharing insights and challenges from their own research projects. Over the next two days, these small groups reconvened to engage in focused applied work, undertaking structured qualitative data analysis exercises and weighing up the value of different methodological strategies for integrating empirical and normative ethical analysis.

On the second day, we turned to the challenges of research design and empirical methods in bioethics. The role of different forms of data was discussed, and the value of qualitative research to addressing ethical questions was interrogated. Much of the afternoon was devoted to one of the central challenges of conducting empirical bioethics research: how to identify ethically relevant content within large empirical datasets.

Finally, on day three, the full methodological integration of the empirical and the normative was put firmly under the microscope. Typologies of integration were laid out and dissected, different methodological approaches to integration were workshopped, and three leaders in the field offered personal stories of their journeys into and through empirical bioethics.

One of the most enjoyable elements of the Summer School was the emergence of a new network of likeminded scholars committed to learning from each other and sharing their research insights and experiences moving forward. Transcending the usual expectations of a classroom-based educational activity, the

Summer School morphed into a welcoming and open space for workshopping new project ideas, different theoretical foundations, and innovative methodological practices. Evening social activities no doubt also helped to bring participants together and to identify shared interests beyond individual research projects.

Demand for the Summer School was overwhelming and far greater than we had expected, with 4 times more applications received than places available. Tough decisions had to be made, and some excellent PhD students, post-doctoral researchers and other junior academics missed out. Those who participated provided very positive feedback, and we look forward to collaborating further with them in the years to come.

Because of the strong demand for the first event, we are glad to be able to announce the next iteration is planned for **December 12th – 15th 2023** in Amsterdam: a Winter School in Empirical Bioethics. Save the date! Further information will follow through the usual EACME channels of communication. We also have grand plans to take the program on a world tour in future years…

PhD Thesis summary

Time, Life & Memory; Bergson and contemporary science

Laurens Landeweerd

Henri Bergson (1859 1941) was one of the most widely read philosophers of his era. The European public was seeking for answers to questions of the soul and the nature of life and fitting within a historical niche between intellectual rationalism and intuitive spiritualism, his writings drew much attention. But after the 1930s, enthusiasm over his work dwindled. This study that revitalises Bergson's ideas for current developments in exact sciences. It explores the relevance of Bergson's thought for contemporary philosophical reflections on three scientific research domains: physics, the life sciences and the neurosciences. It does so on the basis of the three interrelated topics of time, life and memory. It discusses of physics in relation to the abstract and the concrete, the life sciences in relation to concepts of life in their relevance for new and emerging biotechnology, and the neurosciences in relation to the dual nature of human identity. The focus is however on one topic: time. Time in its problematic nature as constant renewal in modern physics; time in its manifestation of the processes of evolution in biology; time as phenomenon sprouting from the faculties of memory and imagination in neuropsychological accounts of the human being. Landeweerd thus frames time as a living process, rather than as an instrument for the measure of events. This view forms the basis of a novel approach to the philosophy of technology for the Anthropocene.

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PhD Thesis Summary

Withholding Information as Desirable?
A Taste of Confucian Bioethics

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As an increasingly common element of a modern healthcare system, palliative care has gained rising attention from the academia and the public. Until today, a comprehensive palliative ethics has been established in the West that argues end-of-life care should be a holistic care aiming at addressing a patients' total pain and improving a patient's quality of life; the care should be provided by a multidisciplinary team and the main instrument should be the prevention and relief of suffering (WHO, 2020).

Nowadays, palliative care is not only integrated in the healthcare systems in most developed countries, but also established in many developing countries, for example, the focus of this article – Mainland China. China started to provide this service in the 1980s (Yu, 2020). As nothing similar had existed in China before, the care delivery systems here were adopted in a rather straightforward manner from the more developed West (Luo, Zhang and Li, 2020). Thus, China has encountered many similar problems to her Western peers during the development. For instance, the coverage, the availability and the accessibility of the services appear to be limited (Ning, 2018; Chen, 2020; Hui and Bruera, 2020). The resources of personnel and training are also in short supply (Luo, Zhang and Li, 2020). However, there are certain aspects in ethics that show significant divergence. The most outstanding debate is the one about truth-telling.

Let's begin with the more familiar Western model. In the West, palliative care ethics, or contemporary medical ethics in general, is largely built on the secular liberal ethics (Woods, 2007). Individuals are entitled to have the most power in decision-making, and such right should be least interfered by other agents and authorities. In addition, to facilitate better decision-making, individuals should be provided as much information as possible (Cherny and Portenoy, 2021). Another feature observed is that the interaction in the West appears to be a dyadic relationship between the doctor and the patient. Therefore, while coming to the specific case of truth-telling, the patient should be fully informed to make autonomous choices, and the professionals are legally obligated to provide any information relevant.

Nevertheless, in Mainland China, an opposite attitude towards information disclosure can be witnessed. In Chinese culture, withholding the malignant diagnosis is often considered as morally acceptable or even desirable (Huang et al., 2014; Fan et al., 2019; Pun et al., 2020). The reason is that such information can cause adverse psychological distress and suffering to the patient (Zhang et al., 2021). If the patient is not told about such information, the potential consequences can be avoided. To decide whether and which information to be withheld, the professionals normally talk to the family first. The family – often the spouse and the adult children – then have a private, collective discussion to handpick what can be known by the patient. In this process, three parties are involved: the family, the patient and then the doctor, and the family appears to be the most dominant player.

This family-led model derives from the most profound philosophy in Chinese societies, Confucianism. In contrast to individualism in the West, Confucianism suggests a social personhood and accordingly, an other-regarding society (Hui, 2002). One's individual status, whether social or moral, needs to be obtained, recognised and progressed via interpersonal relationship. Without others, an individual has neither identity nor virtues. Moreover, Confucianism indicates that personal identity is inseparable from the moral duties attached (Wang, 2002; Cong, 2004; Fan, 2006). One's identity and prestige can only be recognised once the according responsibilities are fulfilled.

Such beliefs then shape the vital role of 'the family'. For Confucianism, everything starts from within the family. The family is the first set of interpersonal relationship the individual has, and thus 'the first school of virtues' for individuals (Wang, 2002: 249). The virtue related to the family – filial piety – is correspondingly deemed as the 'root of humanity and morality' (ibid., 250). Filial piety refers to the moral duty to care for one's family members, especially those vulnerable (Wong, 2020). This duty has been extended to Confucian bioethics and transformed to one of its most outstanding features – familism. When familism sheds its light into real life scenarios, it can be substantialised as the collectivist, family-led decision-making model (Zuo et al., 2014). The belief underpinned this model is that according to Confucianism, the act of the collective can generate greater good comparing to the act of the individual. This conviction then profoundly shapes the dynamics in the context of medical decision-making.

Coming back to the case of truth-telling, in China, withholding information from the patient is well justified by Confucian bioethics. Firstly, the duty of filial piety requires the family to participate in decision-making as a form of care (Chan et al., 2012). In addition, to avoid harm from the patient is also an obligatory care responsibility (Zhang et al., 2021). Secondly, based on the principle that collective reasoning is better than reasoning involving only one person, the decisions made by the family are believed to be better than that of the patient alone (Hui, 2002). Therefore, the family becomes the first contact point of healthcare professionals, and most decisions about the patient are made with the family while seldom including the patient. It seems that during the process, the family is deemed as an entity that should be consulted together (Cheng et al., 2012; Raposo, 2019). Thus, such model is named as ‘family autonomy’ in accordance with the format of ‘individual autonomy’ in the West.

However, such justifications, and more fundamentally, the idea of family autonomy, are not very well accepted by some Western scholars. From the perspective of social contract theory, this idea has been accused as invalid as primarily, the duty of filial piety is not established based on mutual consent between the parent and the child (English, 1979; Daniels, 1988). Indeed, the child’s consent is not sought before his birth. Yet in this sense, all parental relationships, whether Asian or Western ones, cannot be morally valid, as children’s consent cannot be obtained before their lives are given. Moreover, it also needs to be highlighted that the spirit of contract is essentially a Western theory. When the duty of filial piety is examined by the native, Confucian principles, it is justified as the necessary premise to validate a familial relationship and one’s identity as a spouse or a child (Fan, 2006). Family autonomy is also criticised as a ‘cultural excuse’ to resist Western norms which are implicitly considered as the more advaced standards (Raposo, 2019: 26). Unfortunately, such a claim may arise from ethnocentric prejudice rather than normative validity.

To conclude, it can be well observed that there are still very obvious distinctions between the Western palliative care ethics and Confucian bioethics. One example is that the practices of truth-telling led by these two philosophies are divergent. Nonetheless, before deciding that norms in Mainland China are ‘invalid’ or ‘unethical’, it needs to be highlighted that such judgements are generally made through a filter of Western normativity. More cautious research is needed to balance such bias and come to a more objective verdict.

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PhD Thesis Summary

Reproductive Genetic Carrier Screening for Monogenic Conditions: Facilitating Informed Choice and Decision-Making

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Reproductive genetic carrier screening (RGCS) allows for 'the detection of carriers of autosomal recessive and X-linked conditions in individuals or couples who do not have an a priori increased likelihood of being a carrier based on their or their partners' personal or family history' (1). Prior to conception, couples at risk can consider different reproductive options like IVF/ICSI combined with pre-implantation genetic testing for monogenic conditions (PGT-M), gamete donation, adoption or refrain from having children together. At risk couples can also opt to have additional testing during pregnancy (prenatal diagnosis) to confirm the presence or absence of the condition in the fetus. When the condition is present, couples can either decide to terminate the pregnancy or to prepare for a child with a recessive condition (1).

The idea of population-based RGCS programs have raised many ethical and (psycho)-social concerns that should be taken into account to be able to ensure a responsible implementation.

As the availability and accessibility of RGCS is growing, more couples will be presented with the choice to accept or decline such an offer. Their attitudes and beliefs, as well as the perceived usefulness of this screening modality will likely determine whether RGCS is to become a widespread reproductive genetic test. More insights are therefore needed to understand how individuals and couples process information when RGCS is offered to them and which factors affect couples decisions to undergo or forgo RGCS. In Belgium, the Superior Health Council (SHC) recommended that RGCS should be made available to all couples considering pregnancy (2). However, the SHC also recognized that to ensure a successful implementation a number of challenges would need to be addressed, including the interest and participation rate of the target population and how to ensure adequate pre-test information/counseling and post-test counseling to facilitate informed reproductive decision-making. The present project addresses these recommendations of the SHC.

The general objective of this PhD research project was to study informed choice and reproductive decision-making with regard to RGCS for expanded test panels of monogenic conditions. Specific objectives were (1) to synthesize evidence from empirical studies that assess the interest in RGCS among individuals and couples in the general population, (2) to gain insights into the potential impact of RGCS on the subsequent reproductive decision-making of at-risk couples, (3) to assess the perceived susceptibility of being a carrier/conceiving a child with a hereditary condition, the acceptability of offering RGCS, the intention to participate in RGCS, knowledge of RGCS, attitudes towards RGCS and preferences for the practical organization of a RGCS offer amongst men and women (of reproductive age) in Flanders (Belgium), (4) to implement and evaluate a RGCS offer in a reproductive context among non-pregnant couples.

To meet objective (1) and (2) we performed two systematic reviews of empirical literature (3, 4). In line with objective (3), we have reported findings of two cross-sectional survey studies on the perspectives of reproductive-aged women and men with regard to RGCS (5, 6). Finally, we performed a longitudinal survey study through a gynecologist practice in Flanders (Belgium) (a) to study the interest of non-pregnant couples in a preconception RGCS offer, (b) to assess the extent to which couples make informed decisions regarding participation in preconception RGCS and (c) to assess the level of satisfaction, anxiety, long-term knowledge retention, psychosocial & counseling related aspects among couples who choose to have reproductive genetic carrier screening (7, 8).

Our results show that there may be discrepancies between prospective parents' reported intentions to undergo RGCS and their actual uptake, particularly during the preconception period. Offering preconception RGCS was associated with a lower uptake compared to prenatal RGCS which could mean that RGCS is perceived to be more relevant during pregnancy. An exception to this finding was the observation of a high uptake for RGCS among women who were counselled in preparation for IVF (9) . Couples seeking assisted reproduction might be particularly interested in RGCS (4, 10) and health care professionals might be more inclined to direct patients preparing for IVF/ICSI to have RGCS because they are easier to reach during the preconception window and because of the immediate availability of PGT-M following positive screening results (9). More research is however needed to assess the intention to participate in RGCS among couples seeking assisted reproduction, their reproductive choices after 'positive' results, the psychosocial impact of screening within this specific context, the impact of possible tensions between a doctor's professional responsibility and the reproductive autonomy of patients, etc. (10).

Most couples with an increased likelihood of conceiving a child with an AR or X-linked condition chose reproductive options to reduce the risk of a child affected. Most non-pregnant couples pursued IVF/ICISI with PGT-M, while pregnant couples most often underwent prenatal diagnosis followed by an elective termination of an affected pregnancy (3). However, some identified carrier couples also decided to accept their reproductive risk and declined any further testing. The severity of the clinical phenotype seems to influence reproduction decision making, as alternation of reproductive plans was less likely for less severe clinical phenotypes. Nevertheless, primary studies included in our systematic review also reported heterogeneity in reproductive decisions of carrier couples for the same monogenic condition. This suggest that other factors could also influence reproductive decision-making (e.g. negative view towards pregnancy termination) (3).

Most of our survey study participants showed positive attitudes towards RGCS and found it acceptable to offer RGCS to couples planning a family. Self-reported intention to have RGCS didn't always translate into actual test-uptake. Within our study where the Belgian RGCS test was offered free of charge to non-pregnant couples from the general population, 53% of women (meeting our study inclusion criteria) who initially showed the intention to have RGCS decided to accept the offer. We observed high rates of informed choice among non-pregnant couples who accepted a free RGCS offer after they were offered up to 30 minutes of pre-test counselling. We argue that pre-test counselling initiatives for RGCS should ideally be organized in such a way that information can be provided at multiple time points to avoid information overload and to allow for a reflection period. Providing information in advance could facilitate efficient and effective pre-test counseling (11). Interactive education tools like a patient decision aid could help clarify theoretical concepts in a non-directive way and stimulate a process of deliberation in settings with limited resources.

We recommend that RGCS should ideally be implemented through a tailored implementation strategy whereby individual needs and preferences can be taken into account. Future research should try to assess if high levels of informed choice can also be achieved outside a controlled research context with more limited resources.

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TEAM PARTICIPATION IN THE EACME CONFERENCE IN VARESE

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This year's annual EACME conference 2022 was framed by the topic 'Enhancing dialogue to bridge the gaps in bioethics' and this theme drew a diverse group of ethicists to Varese. The Centre for Biomedical Ethics and Law from KU Leuven (www.cbmer.be), Belgium, decided to participate in this EACME conference as a team. In this way, we tried to strengthen the first aim of the EACME conferences: "Offering opportunities for both senior and junior researchers to present their work to a broad international audience" (www.eacmeweb.com).

Below, we share with you the impressions of some of our young and senior bioethics researchers who attended the conference. They all show the value of 'enhancing dialogue' between ethicists working in various centres in Europe. Through these international dialogues, the attitude of openness and attention for specific contexts can be cultivated. EACME can further these exchanges, through organizing meetings and supporting scholars to attend them. But we also enjoyed the team-building dimension of our participation in the EACME conference, especially after 'two years of isolation' during the Covid-19 pandemic. The KU Leuven team left Varese filled with enthusiasm and inspiration to start the new academic year full of research challenges that lie ahead for medical ethics in Belgium and throughout Europe.

What did we appreciate in attending the EACME conference in Varese as a team?

"Networking, discussing, and observing presentations with international world-renown scholars was a great privilege. Plus, experiencing the Italian culture, history, and food with my colleagues from the Centre for Biomedical Ethics and Law (CBMER) almost made me feel like I was on holiday! EACME and the University of Insubria have my thanks for making this conference a memorable one." (Andrew Barnhart, PhD student)

"It was my first time attending such an important academic venue, and a privilege witnessing presentations from high-level scholars from all over Europe. Networking, sight-seeing, and participating with my CBMER colleagues really made it a memorable experience." (Jacopo Ambrosj, PhD student)

"I really enjoyed this year's EACME conference. It was my first time attending and I found the dialogue that came out of the many great parallel sessions quite intellectually stimulating. It is nice to meet peers and see what they are working on and how it relates to my own research, and therefore I appreciated the attention given towards young scholars. The setting was great too! The Varese sunshine is hard to beat. Looking forward to the next EACME conference!" (Jared Howes, PhD student)

"As expected, the EACME conference was a great success, with many attendees who showcased their excellent research. It was a pleasure to meet researchers from all over Europe and the world. What I found most special was how this event helped bring us together as a group – through travelling together, exploring pretty Varese and enjoying the gala dinner, we learned much more about each other than we would have at work. It feels to be back to this pre-Covid level of fun! A huge thanks to the organizers for their efforts that made for such a pleasant time." (Roshni Jegan, PhD student)

"After the Covid-19 period, it was good and important to bring all researchers together at a nice conference. The EACME conference was a nice opportunity to present work, interact with other researchers, but also to strengthen ties in the team." (Pascal Borry, Professor)

"It was a pleasure to participate in the EACME conference held in Varese. It was so nice to have this opportunity to present my work in this international occasion, and to discuss ethical issues with other European colleagues. I talked a lot with some colleagues from UK, Italy, and Switzerland, so pleased to know their topics and to understand ethical issues in their countries. The conference was perfectly organized and I felt very comfortable staying those days." (Yajing Zhong, PhD student)

"The conference focused on a very crucial and central aspect. Dialogue should be central, not just in bioethics, but also in the other disciplines. I enjoyed the exchange of ideas and the possibility to start new collaborations, not just among centres, but also among individual researchers." (Daniel Pizzolato, PhD student)

"The EACME conference was an amazing opportunity to discover a large array of very interesting bioethics projects carried out in Europe. On a more personal level, I allowed me to reconnect with some old colleagues, meet new colleagues, and spend some great time with my current colleagues." (Alice Cavolo, Postdoc researcher)

"Being there as a team was great. It was wonderful to see how our various young scholars – ranging from 'early stage', over 'more experienced', to 'nearly finishing their PhD project' – were engaged and supportive towards each other in their presentations. By exchanging ideas, learning by doing, sharing their knowledge, they all flourished and evolved as young academics in an international setting. For me, as professor at the Center, it was really interesting to hear them speak and learn more bout the various projects of your colleagues. And of course, it also created a wonderful group dynamics, laughing and cheering, getting to know each other better in person." (Yvonne Denier, Professor).

"It was my first time attending the EACME conference as a fresh PhD-student and it was a great pleasure to hear and meet people who are involved in the same research area. I particularly enjoyed the friendly atmosphere, the beautiful surroundings of the first venue and the conference dinner location, as well as several talks that have provided me with food for thought regarding my own work. Also, the opportunity to present a recent study that we did with our team and to discuss this with people attending my talk was a very helpful and interesting experience. I am already looking forward to participating in future EACME conferences." (Kamiel Verbeke, PhD student)

New EACME Board Member: Presentation of ETØK and Motivation for Board Membership

Kristine Bærøe
ETØK, University of Bergen

I represent the section Ethics and Economics (ETØK), at the Department of Public Global Health and Primary Medicine, University of Bergen, Norway. This section is organized into two research groups: Bergen Center for Ethics and Priority Setting (BCEPS) and Health Economics, Leadership and Translational Ethics (HELTER). The research groups are separated mainly for administrative reasons; they partly overlap with each, co-operate and cover together a variety of bioethical areas: priority setting in health, health economics, clinical ethics, leadership, research ethics, political philosophy, environmental ethics, global justice, ethics of biotechnology and artificial intelligence in health, and meta-ethics. For more information about ETØK, please see: Section for Ethics and Health Economics | University of Bergen (uib.no)

As a board member I would like to actively engage in shaping the future of EACME. More specifically, I will aim to contribute by accommodating knowledge exchanges of medical ethics across borders and EACME institutions also outside the annual conference, by for example arranging online webinars. According to data from the Uppsala Conflict Data Program and the Oslo Peace Research Institute, there were at least 56 active armed conflicts in 2020, which have cost the lives of at least 50,000 people in that year. The United Nations High Commissioner for Refugees estimates that 82.4 million persons have been forcibly displaced in 2020 (of whom 35 million were children), and that this number has again risen since then.

Presentation Host of EACME 2023: Center for Bioethics and Biolaw, University of Warsaw

The Center for Bioethics and Biolaw (CBB) was established in 2015 at the Faculty of Philosophy, the University of Warsaw. It brings together both experienced and young scholars working on ethical, legal, cultural, and social aspects of medicine and life sciences. CBB is a full member of the European Association of Centres of Medical Ethics (EACME).

CBB cooperates with the International Academy of Medical and Public Health Network and hosts the Polish Unit (Warsaw) of the International Chair in Bioethics.

CBB members have been involved in numerous national and international interdisciplinary research projects, including “Healthcare as a public space: social integration and social diversity in the context of access to healthcare in Europe” (funded by Humanities in the European Research Area program), “Body, person, and informed consent. Ethics of using human body in medicine and research" and "Ethical analysis of risks and potential benefits in biomedical research", "Legal responsibility of cognitively enhanced persons" "Indecent proposal? Ethics of paying participants of biomedical research", "Ideas of progress and development in the context of climate crisis in peripheral philosophies in XXI century" (funded by National Science Centre) and "Development of participatory bioethics" (funded by the Ministry of Education and Science). CBB members have published more than one hundred papers and seventeen books.

The leaders of CBB are active members of many international and national bioethical bodies, including the European Group on Ethics in Science and New Technologies (EGE) (Paweł Łuków), the WHO Research Ethics Review Committee (WHO ERC) (Joanna Różyńska) or the International Bioethics Committee of UNESCO (IBC) (Joanna Różyńska).

CBB provides scholarly support to the MA program in Bioethics, the only bioethics program in Poland. The courses focus on the ethical, legal, and social challenges of the development of biomedical sciences and new technologies, global public health, global climate crisis and sustainable development. Students acquire unique competences, which are essential, among others, for medical professionals, public service employees, policymakers, non-governmental organizations employees and teachers.

The Center for Bioethics and Biolaw is also involved in various activities aimed at development of bioethics as a social practice and public discourse. It closely collaborates with the Committee of Bioethics and with the Committee of Ethics in Science of the Polish Academy of Sciences. They collaborate in order to develop educational programs in bioethics (i.e., annual Spring Schools in Bioethics) as well as to raise ethics awareness in academia.

For more information, please visit:
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Book Review

Véronique Fournier and Nicolas Foureur
Éthique clinique. L'éthique clinique en 10 cas. L'éthique clinique en 10 repères méthodologiques
Ed. Dunod, Paris, 2021

By Maria Aluas

This book is an honest and sincere testimony of over twenty years of experiencing clinical ethics in France. The two authors, Véronique Fournier and Nicolas Foureur are both physicians and clinical ethicists at the Center for Clinical Ethics (Centre d'Ethique Clinique) within the Hôpital Cochin in Paris, France.

The book was published in 2021, at the Dunod Edition, in the collection Aide-Mémoire (Check-List). The "aide-memoire" concept was imagined more than 150 years ago, by Charles Dunod (see the website at https://www.dunod.com). The concept aim is to collect dispersed knowledge with immediate practical relevance. It allows readers to memorize, learn, consolidate, update their knowledge, and put it into practice.

The book presents, in an original way, a guideline in clinical ethics for healthcare personnel first, but also for everyone who wants to improve its professional expertise in this field. The clinical ethical frameworks are illustrated in 2 parts, 10 cases and 10 methodological points. Each part contains 10 chapters with an introduction where authors present and motivate their topics. The book opens with a foreword (Avant-propos) written by Véronique Fournier, where the first sentence states that: 'the clinical ethics is a method', at least the clinical ethics which will be discussed in this book. The central key point of their approach of clinical ethics is the multidisciplinarity with the main purpose to rebalance the patient's voice, as person, not only as patient and to improve the quality of medical services for the patient. Afterwards, she describes the clinical ethics, the beginnings of this field in France, the difference between medical ethics and clinical ethics method.

The first part, Clinical Ethics in 10 cases and 40 questions, presents 10 situations related to beginning of life issues (assisted reproductive medicine, obstetrics, neonatal intensive care, pediatrics), psychiatry, geriatrics, end of life decisions, authors and their team faced in their practice. Each case is followed by 4 ethical questions related especially to the patient's context; the place of the laws, religion, and culture; ethical principles (autonomy, beneficence, nonmaleficence and justice); patient's proxy, the role of the patient family; discrimination, disability, vulnerability, sexuality. The end-of life choices are framed within the French cultural and legislation context: delimitation between end of life and ending life, how to understand the active help to die, the difference between speak for yourself of for other.

In the second part, Clinical Ethics in 10 methodological points of reference, authors expose their method of clinical ethics practice, such as: the ethical reference chart, the referral (fr. saisine), instruction, lists of elements to explore, the clinical ethics staff, the monitoring, the summary of key steps, the most frequent 10 questions raised by cases and 10 elements of contemporary French context. In the last chapter, written by Nicolas Foureur, the author exposes readers his journey in clinical ethics started in 2005, 3 years after the clinical ethics support was implemented in France. The author argues in favor of clinical ethics for renew the healthcare personnel working experience.

In my own perception, the book's strengths are its practical dimension, being a clear orientation for healthcare personnel, the clear and concise way of describing their method of work, the language used accessible to everyone interested on the matter. Reading the book in an enriching experience, the cases, ethical questions raised by cases and tools for acting in clinical ethics 'adventure' broaden the knowledge of clinical ethicists understanding of French cultural, medical, and legal context.

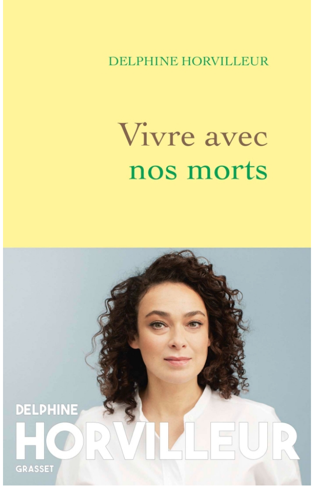
In the end, I would like to thank authors for giving me the possibility to assist in person, as a guest, one of their clinical ethics sessions. The case was related to geriatrics and disability topics, patient's preferences, and lack of family (proches). I was impressed by how they handled a very complex and emotional case and moderate the session giving voice and place to all parties involves. For me, this was the first time when I have assisted to a clinical ethics session, and I was impressed by their work and by participants professionalism (they were all healthcare personnel).

This book is a great work, over 20 years of clinical ethics experience concentrated in 10 case, 40 ethical questions and 10 methodological key points.

Book Review

Delphine Horvilleur
Vivre avec nos morts
Paris : Grasset, 2021

By Jean Martin



Es gibt eine Übersetzung auf deutsch : «Mit den Toten leben». Berlin : Hanser. An English version is in preparation, under the title «Living with our dead».

Delphine Horvilleur (née en 1974) a commencé des études de médecine puis est devenue un rabbin libéral. Elle publie un livre sur l'accompagnement des personnes en fin de vie et de leurs proches. Contant une douzaine d'histoires, décrivant son expérience tout en y ajoutant les réflexions de penseurs juifs. « Mon rôle est d'« accompagner les endeuillés, non pas pour leur apprendre quelque chose qu'ils ne savaient déjà mais pour leur traduire ce qu'il vous ont dit. »

Sur la question des enfants et petits-enfants de personnes disparues durant la Shoah : « Ces enfants 'nés après' sont devenus les parents de leurs parents. Souvent, ils cherchent à les réparer (…) Ce syndrome de l'enfant-messie est décuplé dans les familles traumatisées. »

« Accompagner la mort des autres ne n'a pas immunisée contre l'appréhension de la croiser. Je me méfie de tous ceux qui disent qu'il existerait une méthode imparable pour l'accepter. » A propos de la mort d'un enfant : « Elle vous condamne à l'exil sur une terre que personne ne peut visiter, à part ceux à qui il est arrivé la même chose. »

« Ainsi vont les saisons, les arbres et les hommes ne continuent à vivre que si la mort les visite. Le printemps ne vient que pour celui qui traverse l'apoptose, et laisse la mort sculpter la possibilité de la renaissance. »

J'ai été particulièrement touché par les deux derniers chapitres. Un, poignant, sur sa participation à la grande manifestation, en novembre 1995, où le premier ministre Itshak Rabin a lancés des appels forts à la paix, quelques minutes avant d'être assassiné par un fanatique. Et celui où elle se rend dans le village alsacien d'origine de sa famille, Westhoffen, après que son cimetière ait été profané en 2019.

DEADLINE NEXT NEWSLETTER

The deadline for the first edition of 2023 is:

April 1st, 2023

An opportunity to promote your event, to inform your EACME-colleagues about the results of your work, descriptions of projects, book reviews, webinars etc.
Any ideas for contributions for the upcoming edition?

Please get in touch and do not hesitate to contact our editor Caroline Brall: caroline.brall@unibe.ch

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