EACME Newsletter

EUROPEAN ASSOCIATION OF CENTRES OF MEDICAL ETHICS

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Dear EACME colleagues and friends,

This year, we are unfortunately faced with another challenge in addition to the Covid-19 pandemic: the war in Ukraine. It is incredibly sad, devastating and incomprehensible to witness what is happening to a close neighbour in Europe. It is not an easy task to grasp the many challenges which arise from this and we are unfortunately also seeing the medical ethics challenges, among them for example the humanitarian crisis and scarcity of resources, migration and new vulnerabilities and many other. Besides these challenges, where medical ethics might provide some theoretical guidance, the field and profession of medical ethics is challenged itself in these times: what can the field of and community of medical ethics – a moral discipline in itself – do to actually support Ukrainians. What *ought* it do? EACME is currently planning a webinar to think and discuss on this issue.

In this edition of the EACME Newsletter, one special contribution also highlights the discipline of bioethics itself and its challenges and opportunities in the years to come. The past presidents of EACME together wrote a contribution about their discussions in personal conversations about the developments in bioethics. With this they let us be part of these conversations on "What we deem important currently in our discipline of bioethics".

In view of the past pandemic years, EACME recognised that especially early career researchers had novel challenges to overcome, less chance to practice presenting and discussing their work, and also fewer opportunities simply to meet and talk with their colleagues, both in their home country and around the world. EACME aims to provide a platform for early career researchers to connect and will therefore host a first webinar/meeting especially for early career researchers in June. Please see more information in the announcement section below. We are looking forward to 'expressions of interest' from all early career researchers and PhD students in your centres.

Very best wishes,
Caroline Brall

NEWS FROM THE EACME BUREAU

Dear EACME members, dear colleagues and friends

We hope this Newsletter finds you, your colleagues and families well and in good health. Furthermore, our sincerely thoughts go out to all those who are hit by the current war in Ukraine. Words might quickly sound banal or cliché, yet we want to express our compassion to all involved. It is awful to see the devastating impact and consequences, material and immaterial, of this war.

With respect to the news of the Bureau: As earlier announced in the Friday News, Kim Zandvliet left the Bureau due to a new job at the VU University in Amsterdam. We thank Kim for her support and work for the EACME Bureau and for EACME as a whole! Being a new secretary of the EACME Bureau is not an easy task: something we realized even more when Angelique Heijnen left us after decades. Yet, to our surprise and great relief, due to changed circumstances in her life, Angelique was able and also motivated to join the EACME Bureau again! So, we are very happy that Angelique is with us again.

Two new changes took place in the Bureau. Since we had two new members joined the Bureau last year, we thought it would be worthwhile to describe the tasks and roles of each Bureau member more explicitly. We would like to thank our former EACME presidents Rouven Porz and Ruud ter Meulen for their help. This new document is a way to professionalise the Bureau: it makes the tasks and roles of each Bureau member more transparent, it is helpful in our annual self-evaluation, and is also informative for new Bureau members in the future. The second change is the fact that we decided to expand the Bureau by a fifth member ('strategic adviser') this autumn. Decisive in this decision was the fact that the EACME is expanding and additional expertise in the Bureau will be useful to distribute the work among the Bureau members and to create more opportunities for international networking and involving other medical ethics centres.

Furthermore, as Bureau we are aiming for more interactions between the Board and the Bureau. Therefore, we organised an extra Board-Bureau meeting this month (usually the Board and the Bureau only meet once a year during the EACME conferences). We had a very good and inspiring meeting last week and we discussed plans for a series of new EACME Webinars. We also made plans to involve young scholars and PhD students more within the EACME community and will soon communicate these to you.

As Bureau we will travel to Warsaw in May to visit Pawel Lukow and his team for preparing the EACME conference in 2023. It will be the first time that we as Bureau members will see each other live! Of course, we are only in the process of starting to organise the Warsaw conference, but we are impressed by the first ideas and preparations of Pawel and his team.

Last but not least: the Varese conference is almost there! Mario Picozzi and his team have

prepared a wonderful program, with a nice list of high-quality speakers. It will be wonderful to see each other again in person in September! The deadline for abstracts has been extended to the second of May, so please remind your colleagues again to submit an abstract and bring your research expertise, experiences and your colleagues themselves to Varese!

Warm wishes, on behalf of the Bureau (Ruth, Federico and Angelique)

Bert Molewijk

What we deem important currently in our discipline of bioethics

Rouven Porz, Chris Gastmans, Ruud ter Meulen, Renzo Pegoraro, Paul Schotsmans, Guy Widdershoven (EACME past presidents)

Our discipline, bioethics, has developed - from pioneering beginnings in the 1970s - into a mature discipline. But with this maturity come new challenges. In this text we would like to outline a few thoughts that seem important to us in the current state and in the near future of bioethics. Why is this important to us? We have witnessed these developments. The authors of this text have all been presidents of the EACME at one time. EACME and bioethics are very close to our hearts, and we have often found ourselves discussing developments in personal conversations, and trying to anticipate on the future.

Recently, the Corona pandemic has shed new light on our discipline. The pandemic in a way has changed our discipline, as there have been many media enquiries, ethical issues have been dealt with in public, teaching has switched to video-conferencing, and annual conferences are taking place now in a virtual or hybrid form.

So, maybe it is time to pause for a moment and reflect. We present our thoughts on the current situation in bioethics in bullet points, not with the claim of completeness, and certainly not with the claim of a final truth, rather as food for thought:

- **Avoiding a rift between academic ethics and clinical ethics**:

In the last 20-30 years our discipline has moved closer to the scientific research paradigm, and a career in bioethics is generally built on high-impact publications and the ability to acquire research funding. This is how many of us work, especially if we are employed in academic ethics at the university. At the same time, however, the more practice-oriented field of clinical ethics has emerged, ethicists who work in hospitals with healthcare staff to provide ethical support in moral issues related to clinical care on a day-to-day basis. Often, although not always, the focus on clinical practice precludes excellence in academic research. There is therefore a danger of

a rift between academic ethicists and clinical ethicists in our own discipline. We should avoid that. Both sub-disciplines complement each other, we should see the mutual benefit for bioethics as a whole, and both academic ethics and clinical ethics should strive to work together in job application procedures, publication projects or in conference participation, rather than exclude each other. There should also be no suggestion that one is more valuable than the other.

- **Reconciling empirical and theoretical approaches**:

Bioethics started with theological and philosophical approaches to moral issues in clinical medicine, to be joined later on by empirical sciences like sociology and policy studies of health care and (bio-)medical technologies. Bioethics then is a multi-disciplinary project which has a wide range of issues and topics as the object of its studies. However, since the 'empirical turn' around the end of the last century, there is an increased emphasis in bioethics on empirical methods (qualitative studies, interviews, survey studies) to investigate moral problems in medicine and health care, often at the expense of theoretical studies in this field. Moreover, these empirical studies risk to remain rather descriptive, lacking a thorough connection with philosophical analysis and more prescriptive approaches. In view of this development, we argue that theoretical approaches in bioethics, for example the study of theories (virtue ethics, principlism, pragmatism), concepts (autonomy, justice, solidarity) and methodologies, should be encouraged and not be excluded from funding because they are not 'empirical enough'. Only by supporting and nurturing theoretical as well as empirical approaches, bioethics can remain its truly multi-disciplinary character. Still, this dialogue between the results of theoretical ethics and empirical ethics remains a difficult issue. More work should be done not only on the further development of the theoretical and empirical methods in biomedical ethics separately, but also on how these two methodological approaches complement each other and enable researchers to get a rich and in-depth insight into complex ethical issues in healthcare.

- **Combining knowledge based and experience based teaching**:

Bioethics teaching has proven to be important in the past decades, first in the medical curriculum, and later in the education of all kinds of healthcare professionals. Teaching often focuses on knowledge of ethical principles and legal regulations. These are important frameworks for those who work in healthcare. The notions of respect for autonomy and informed consent, for treatment as well as research, are cornerstones of any bioethics teaching program. Yet, knowledge about principles and rules is not enough to guarantee that professionals engage in responsible care practices. It is crucial to encourage professionals to recognize moral tensions in practice and to reflect on moral dilemmas in their day-to-day work. Applying principles and rules requires a feeling for the situation, and the awareness of various perspectives involved. Moral behavior is not the same as following rules; it requires a virtuous character, enabling the professional to know the right middle in concrete circumstances. How to provide information without making the patient anxious? How to secure genuine cooperation beyond merely asking a signature on the consent form? Bioethics has to design ways of teaching which combine knowledge of core concepts and rules with the development of moral wisdom.

- **Contextualization of ethical problems in healthcare**:

Ethical problems in healthcare do not appear in a vacuum, but are highly embedded in a relational, organizational, and societal context. Moreover, the context sometimes contributes in one or another way to ethical problems as is clearly illustrated by experiences of moral distress in nurses and more recently also by stories told by physicians. Medical ethicists should take into account the contextual embeddedness of ethical problems and how this

context might contribute to the solution of ethical problems in healthcare.

- **Emphasizing that ethics is not morality**:

In the coverage of the Corona crisis, ethicists suddenly came into the public eye. Many of us gave interviews for newspapers, radio and television. While we are used to thinking in terms of detailed ethical arguments and reasoning, the media wanted to hear simple and clear moral advice. This has embarrassed some of us time and again. We had to learn that the public is probably not the right place for developing a precise argumentation, but at the same time we do not want to leave our field to superficial moralists. We think we could still learn a lot here as a discipline. Perhaps special training for us ethicists on how to present complex issues in public would be helpful. We should look for good ways to present ethics as a reflection on morality without simply making moral judgments.

- **Combining digital and face-to-face interaction**:

In the time of the recent pandemic, many of us experienced digital teaching and other digital meetings in the field of bioethics and clinical ethics. The use, because of urgent reasons, of digital tools was for many quite new, with the need to prepare a different way to teach and to discuss ethical issues in the area of biomedicine. This new way of interaction appears to have clear advantages. We need less time for traveling, which is also relevant from an ecological perspective. Digital communication can be supported by specific tools, which are more advanced than those we were used to in classical ways of teaching and meetings. Yet, also disadvantages can be noticed. True and participatory discussion, not just sharing of information, is necessary in bioethics. This is not easy online. How to integrate emotions and feelings, important components of moral education and deliberation? Does digital mediation affect the “courage of truth”, the possibility for everyone to express their personal opinions or objections and enter into a fruitful process of learning and education? What are the implications of the possibility of recording lectures and meetings, both for privacy and truthfulness of communication? It will be necessary to find a space of discussion and discernment to decide what to maintain in a digital way, and what requires in-person learning and communication, in order to find a way to combine both in the best way and improve ethics education and moral deliberation.

In conclusion

Our discipline of bioethics has rapidly developed over the last decades. The Corona pandemic has brought the importance of ethics reflection more to the fore, and has also provided new challenges concerning the role of the discipline in the public arena and core activities such as teaching and fostering moral deliberation in practice. We are convinced that EACME can be the place to discuss these issues further, and find new avenues to the future of bioethics.

The Latest Presidents of the EACME:

Paul Schotsmans (1998-2001), Guy Widdershoven (2001-2010), Renzo Pegoraro (2010-2013), Chris Gastmans (2013-2015), Ruud ter Meulen (2015-2017), Rouven Porz (2017-2020)

EACME prize winner 2020

Nienke de Graeff

Nienke de Graeff was the prize winner of the EACME Paul Schotsmans Prize 2020, which was awarded at last year's EACME conference in Cluj. Nienke is a PhD candidate in bioethics at the Department of Medical Humanities at the UMC Utrecht, Utrecht University working on the ethics of new and emerging technologies. Her PhD thesis focuses on the ethics of gene drive technologies. Nienke has an interdisciplinary background in Liberal Arts & Sciences (BSc University College Maastricht, cum laude), medicine (MD Utrecht University) and ethics (MA Utrecht University, cum laude). From fall 2022 onwards, she will work as an Assistant Professor in bioethics at the LUMC, Leiden University.

For this newsletter, we invited Nienke to describe her PhD research and the work awarded with the Paul Schotsmans Prize.

Gene drive technologies: exploring the 'ethical landscape'

In my PhD research, I explore the ethical landscape of gene drive technologies (GDTs) by examining their ethical challenges and investigating how these technologies can be developed in a responsible way. GDTs are technologies that bias the inheritance of a particular genetic element within a population of non-human organisms, thereby promoting its progressive spread across this population. Various types of GDTs using different molecular mechanisms have been proposed, ranging from non-localized gene drives intended to spread throughout a population or species, to localized or threshold-dependent gene drives. If successfully developed and deployed, GDTs may be used to counter several intractable problems. GDTs could, for example, be used to target vector-borne diseases such as malaria and to control invasive species and agricultural pests that humans thus far have been unable to resolve through other means. At the same time, these technologies raise important ethical questions and challenges. It is important to identify and evaluate these in an early stage of technological development to inform the design of these technologies and related governance procedures, and to help guide decisions about whether (and if so, under what conditions) it is morally permissible to conduct field trials with gene drive organisms.

Just like geological landscapes do not appear out of nowhere but have instead been shaped and influenced by all kinds of past processes, the ethical landscape of GDTs has been shaped and influenced by discussions on previously developed, related technologies such as genome editing technologies. As ethicists such as Tsjalling Swierstra and Arie Rip (2007) have previously shown, these 'landscapes' share similar argumentative patterns. Analyzing previous discussions on genome editing technologies can thus help to think about the ethical challenges of GDTs. As a first step in my PhD research, I therefore analyzed the ethical considerations mentioned in the academic literature on genome editing (De Graeff et al, 2019).

At the same time, much in the same way that it is impossible to grasp a geological landscape by merely reading about it, an analysis of the ethical landscape of GDTs that limits itself to a study of the literature may miss important ethical considerations. For this reason, my research on the ethics of GDTs was also informed by empirical ethics research with a wide range of GDT experts. This resulted in the publication of two interview studies which identified various substantive and procedural ethical challenges related to GDTs (De Graeff et al 2021a, De Graeff et al 2021b). Subsequently, my research focused on further conceptual and normative analysis of

some of the ethical challenges that were identified in these publications.

One important ethical challenge that features prominently in the literature on the ethics of genome editing and GDTs relates to the moral permissibility of intervening in nature this way (De Graeff et al, 2019). Indeed, various authors and organizations stress that an evaluation of humans' relationship to nature and their impact on and manipulation of ecosystems play a crucial role in determining the moral permissibility of GDTs (see e.g. NASEM, 2016). The moral views of respondents in our interview study were also principally influenced by their attitudes towards the role humans should have in nature (De Graeff et al, 2021a). In the work that was awarded with the Paul Schotsmans Prize, I normatively analyzed this matter in more detail.

In doing so, I argued that four issues are of central importance in determining whether (a particular) use of GDTs is in accordance with the role humans should have in nature: (1) the moral status of and direct duties towards different (types of) organisms; (2) the prioritization of duties towards different organisms in case of conflicting claims; (3) the moral (ir)relevance of 'wildness'; and (4) the moral status of holistic entities such as species and ecosystems. Subsequently, I reviewed the normative positions that may be taken on these issues and elucidated the central trade-offs and points of contention in the normative debate on the moral permissibility of intervening in the natural state of affairs in this way.

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EACME prize winner 2021

Lars Assen

In September 2021 I have been awarded with the Paul Schotsmans prize for my abstract on understanding responsibility in stem cell research. Currently I work as a PhD candidate in the department of Medical Humanities at the University Medical Centre Utrecht in the Netherlands. My general research project involves the responsibilization of stem cell researchers, which is supervised by Prof. Annelien Bredenoord and dr. Karin Jongsma. In this project, we consider the ethical implications of (induced pluripotent) stem cell research, with a primary focus on the role stem cell researchers should play in preventing and mitigating negative implications and promoting positive ones. My presentation and paper for EACME focuses on identifying what stem cell researchers need in terms of support and skills to take or share responsibility. We hope to share the article that is based on this research later this year.

Responsible innovation in stem cell research: using responsibility as a strategy

While stem cell research sparks hope for new therapeutic options, it is also paired with ethical challenges for responsible research1. Key guidelines and recommendations, such as the ISSCR's2 and WHO's3, underscore the importance of considering responsible research conduct and formulate several responsibilities. What remains unclear is what is meant with the notion of responsibility, how responsibility could be fostered and how individual responsibility is tied to other stakeholders. To effectively deal with the ethical challenges of stem cell research, strategies are needed. The goal of our research is to focus on the concept of responsibility in stem cell research to understand how responsibility could inform strategies to effectively deal with the ethical implications of stem cell research. This could be done by 1) a deeper understanding of how notions of responsibility are related to the ethical challenges of stem cell research, 2) how these notions reveal ties between different stakeholders, such as researchers, research institutes and funding organizations and 3) how these insights could inform strategies and policy to deal with the ethical implications of stem cell research.

The overview that is provided in this article helps to think about responsibility as a set of different strategies to deal with ethical implications of stem cell research. As such, we focus on different notions of responsibility4,5,6. The notion of (1) responsibility-as-accountability focuses on answerability and functions to promote research integrity and restore moral trustworthiness. The notion of (2) responsibility-as-liability, focuses on judgement, punishment or reward of an individual or group or researchers. The notion of (3) responsibility-as-an-obligation involves that by attributing responsibility to specific persons or groups, it ensures that those responsibilities are fulfilled. Moreover, it can be strategized to increase effectiveness of promoting positive research outcomes and to effectively deal with ethical implications that result from technological and scientific innovations. The notion of (4) responsibility-as-a-virtue helps to consider which competences contribute to fostering positive and mitigating negative outcomes of stem cell research and which competences help researchers to recognize responsibilities and act on it.

To successfully foster responsibility as a strategy, it is important to establish what is the ethical challenge or range of ethical challenges that should be addressed, who is responsible, who is commissioning or checking the responsibility and which instrument or strategy is used to promote the responsibility. By doing so, our analysis contributes to realizing WHO recommendations and the ISSCR's guidelines and ethical principles. Moreover, while our focus is on enhancing responsible innovation of stem cell research, our analysis could be considered as a precursor for researchers in other disciplines and fields of study. As such, the analysis could be enriched by considering how (other) notions of responsibility offer (different) strategies to realize responsible research and innovation.

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End- of-life decision-making in Neonatology (ENFolDING)

A project presentation of qualitative research in Germany

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Over the last decade, the chances of survival for extremely premature and critically ill infants have im-proved significantly in Germany. This is mostly due to tremendous advances in neonatal intensive care. Increased survival may also result in infants surviving with greatly reduced quality of life. Situations may arise in which it can be questionable to provide intensive care for infants with severe health impairments. A German study

showed that in most infants who die before or after birth, their death was preceded by a change of the treatment goal and redirection from intensive to palliative care (Schulz-Baldes et al. 2007).

In a pregnancy where a high health risk for the pregnant woman or the unborn child has been identified, a decision about the appropriate treatment strategy for mother and child warrants a deliberation of medi-co-ethical norms and values. The same applies to situations in which a neonate is born with a severe health impairment (e.g., with brain damage following anoxia during birth). There are at least two sets of moral questions that warrant deliberation depending on the point in time that health risks are identified: 1.) the question to continue or terminate the pregnancy or 2.) questions whether to initiate, continue or withdraw life-sustaining treatment of an infant. So, a deliberation about such questions might become necessary at different time points: during pregnancy, during birth, or after the birth of an infant. Obvious-ly, during birth, the general conditions for such a deliberation are severely restricted.

Decisions about the appropriate health care approach for (unborn) children with high risks for severe health impairments have to be made under time pressure and great uncertainty. They can pose moral challenges to neonatologists, parents, nurses, and other health care professionals who are involved in them. There are medico-ethical principles, legal regulations, and clinical guidelines in place that guide German neonatologists in such decisions. Yet, the appropriate procedural guidelines for decision-making about life-prolonging treatment in neonatology are currently debated. While some argue for greater par-ticipation of parents in such decisions, with an idea that parents are autonomous, rational persons, others argue for sparing them from the responsibility with an idea that parents themselves are in a vulnerable situation.

To give ethical guidance for such decisions, it is not only necessary to know about the norms and principles that should guide case-based deliberation, but also about the acceptance and implementation of such guidelines. This is where the ENFoLDING project comes in, with an aim to build a bridge between norma-tive requirements and lived experiences of stakeholders in neonatal care. The overarching goal of the project is to make sense of inconsistencies between the ethical discourse and current practice.

Normative premises for end-of-life decision-making in German neonatology

There is consensus that decisions about the appropriate therapeutic goal and consequently the appropri-ate treatment strategy in the health care of neonates warrant a case-based ethical deliberation. In deci-sions about the continuation or termination of pregnancy, the health risks of both mother and unborn child have to be taken into account. In deciding about the medical treatment for both, ethical considera-tions arise from the duties to act in the best interests of the unborn child, in the best interests of the pregnant woman, and to respect the pregnant woman's right to self-determination. In Germany, an abor-tion is lawful if the life or well-being of the pregnant woman are seriously endangered (§218a Abs. 2 StGB). This so-called “medical indication” includes cases where it is expected that a pregnant women de-velops a mental health disorder by giving birth to a child with serious health impairments. From the basic principle of protecting life and preventing suffering arises the duty to act according to the best interests of the unborn infant. Therefore, in addition to the prognosis of survival, an assessment of the future quality of life is required.

In decisions about whether to initiate, continue or withdraw life-sustaining treatment of an

infant, it needs to be determined which courses of action serve the best interests of the child. This is due to the circumstance that newborns cannot exercise autonomy rights. Surrogates must decide on their behalf. In situations where a change of the treatment goal is considered, parents have the duty to act as represent-atives of their infants. Their decisional authority is also regulated in German family law. Parents have to orient their decision toward the best interests of the child, but perspectives might vary based on the par-ents' values. To determine the best interests of their child, careful consideration of the benefits and risks of the intervention options must be made with a focus on his/her future well-being

In both decision-making processes, parents rely on the diagnosis and prognosis presented by the medical team. Because parents are their child's legal representatives and physicians have a professional obligation to serve the best interests of their patients (e.g., by preventing suffering), both parties should have a role in decision-making. However, the extent of involvement of parents in decision-making about medical treatment for their child can vary. The minimum legal requirement is the "informed consent" of the par-ents, but the ethical demands have changed recently. The German neonatal guideline for end-of life deci-sion-making for extremely preterm infants requires shared decision-making (SDM) between the medical team and the parents as a procedural norm (Bührer et al. 2020).

The following arguments are made by the supporters of SDM: The first argument is a deontological argu-ment, that individual self-determination, and personal autonomy are high goods worthy of protection. SDM may be a way to promote self-determined decisions of parents about their children's well-being. This argument leads to the same conclusion as the teleological argument, that parents should be involved because they are directly affected the most by the consequences of the decision. The third argument is rather a legal argument, that acknowledges not only that the decision has an impact on the parents' own lives, but also that they are the child's legal representatives and hence should act on their behalf.

Other arguments are related to empirical claims. Proponents of SDM claim, that SDM has a positive influ-ence on the parents. The mental processing of the experience could be improved through SDM. Feelings of guilt might be reduced, and their participation could have a positive effect on the parents' grieving pro-cess if a decision was preceded by the death of their infant. The same issues serve as an argument against the greater participation of parents: parents could suffer from stronger feelings of guilt if they participat-ed to a larger extent in the decision-making process. One last argument is the argument of preference: parents would prefer SDM over other models for decision making, e.g. an informed consent model or a model where parents "decide alone". This claim relies on the assumption that a majority of parents pre-fers the same extend of participation.

We aim at contributing to the discourse on SDM in neonatology through empirical research. To our knowledge, no study has yet examined the implementation of SDM in the neonatal setting in Germany so far and little is known about the preferences of parents in Germany for their involvement in end-of-life decision making for their (unborn) child. One problem in this field of research is that there is a heteroge-neous understanding of SDM. In some scientific publications, SDM is used as an umbrella term for any form of collaboration in decision-making that is not further defined or described. The different under-standings of SDM make it difficult to interpret normative claims and to determine whether the practice is sufficiently participatory to be in accordance with the norm. So the first task is to develop a comprehen-sive framework for SDM, before issues that are of relevance to the

ethical discourse can be examined. In box 1 we display the aims of the ENFoLDING project.
An ideal vs. reality comparison according to Kon (2009) will be used to evaluate the arguments made for SDM and identify barriers to its implementation.

What the ENFoLDING project aims at:

►Develop a framework on how to explain the parental role preferences for collaborative end-of-life medical decision making between doctors and parents

►Investigate to what extent SDM is implemented in the NICU under study

►Reconstruct parents' perspectives on their experienced role in medical decision-making for their child

Ideal-vs-Reality comparison

A so-called "ideal vs. reality" study starts from the premise of a normative claim - in our case, the proce-dural norm SDM - and then examines to what extent the actual clinical practice corresponds with this ide-al. Research methods for this type of study are in principle all methods that allow for a procedural or summative evaluation of social practice. In practices which are variable, highly complex, and dynamically changing, qualitative research methods are especially suitable for such a study. A qualitative evaluative approach to research is applied to the ENFoLDING project.

The ENFoLDING project

The research project is conducted at a Level III perinatal care center of the University Hospital of Munich (LMU). In the neonatal intensive care unit (NICU) under study, a multi-professional team (doctors, nurses, a psychologist) provides health care to extremely preterm born infants, infants with congenital malfor-mations, or birth-related health impairments. The data acquisition of the project was conducted between 2018 and 2020. The qualitative analysis of the data material is currently in progress. A theoretical frame-work for collaborative decision-making between medical teams/doctors and parents is developed through a synthesis of qualitative interview studies using meta-ethnography. Further, the study entails the analysis of two sets of data: natural conversations about end-of-life decisions in the NICU and qualita-tive interviews with parents after the discharge or death of their infant. The ENFoLDING project is funded by the Federal Ministry of Education and Research (Grant no. 01GY1718).

1) Meta-Ethnography of qualitative interview studies with parents

The aim of this study is to synthesise what we know from other qualitative interview studies on parents' experiences with end-of-life decision-making in neonatology. This study aims to answer the question, how parents derive their role preference for end-of-life medical decision-making concerning their (un-born) infant. The focus is on their expectations of collaboration with the medical team, and especially on whether SDM is deemed more preferable than other forms of collaboration (e.g. an informed consent model). We used Meta-Ethnography to synthesize qualitative interview studies. Studies were included based on systematic literature research. Meta-Ethnography entails a process of seven phases, from out-lining the aim of the synthesis to describing the impact of the synthesis (Cunningham et al. 2019). The key operation of Meta-Ethnography is a translation of concepts from one study to another. First results indi-cate that medical teams at NICUS offer parents a certain role allocation. Based on their initial and retro-spective evaluation of it, parents express a preference for a hypothetical situation (either a situation in the future that will most likely not happen or a situation where they could go back in time and renegotiate the role that they have been offered). Despite of the decision-making model, parents tend to accept the role

that they are offered. Yet, a minority prefers a different role, sometimes a role with more sometimes with less responsibility. Across all studies SDM is not preferred more often than other models for collabo-ration in end-of-life medical decision-making. This results stand in contrast to the argumentation of pro-ponents of SDM.

2) Neonatologist-parent conversations about end-of-life medical decision-making in the NICU

In this study, we aim at exploring to what extent SDM is implemented in the NICU under study. To answer this question, we recorded natural conversations between parents and neonatologists in prenatal and postnatal decision-making situations for (unborn) patients with a high risk for severe health impairments. Audio data were transcribed verbatim. We use qualitative content analysis to analyse the data material. In the analysis of conversations after the birth of the child, we use a framework by de Vos et al. (2015), a previously published study about patients from the paediatric intensive care unit in the Netherlands, to compare our results. Preliminary results suggest that SDM is implemented to a limited extent in the NICU under study. We discuss whether this calls for either a change of the practice (e.g. through training) or a reconsideration of the claim that neonatologists should offer SDM to parents (e.g. through normative deliberation). In conversations during pregnancy (prenatal counselling), we analyse the conversations with a typology of different practice models for collaboration between doctors and parents, that we de-rived from the Meta-Ethnography.

3) Semi-structured interview study with affected parents

In this study, we examine how the parents who participated in the recorded conversations evaluate their experience and what extent of participation they would wish/have wished to have. If parents perceive their involvement in the current approach as beneficial, the normative claim to implement SDM to its full extent, as suggested in the guidelines, would need reconsideration. Parents participated in semi-structured interviews approximately three to six months after the end-of-life conversations and in some cases after the subsequent death of their child. We recorded interviews and transcribed them verbatim. Again, we use qualitative content analysis to analyse the data material. Preliminary results suggest that parents experienced different models of collaborative decision-making and in accordance with the results of the Meta-Ethnography, a majority preferred that type of involvement that they had experienced. There was no majority preference for SDM.

Outlook

We are currently working on the publications of the study results. One of the challenges we are dealing with is determining the transferability of our results. Our empirical material stems from a single NICU in a country where such studies are largely missing. The normative and cultural context of our study probably has a strong influence on whether parents deem their experience with a critical life incident such as deci-sion-making about life-prolonging treatment for their infant as acceptable or beneficial. The communica-tion strategies used by the doctors under study might have been acquired through model learning on the ward and not be representative for other neonatologists. Furthermore, the subjective perspective of the researchers and their interpretation of the normative premises, the value of parental participation in de-cision-making, and the data can have a strong influence on the construction of the results. This issue de-mands self-reflexion of all team members. An advantage, but also a challenge, is that we are analysing the data material in an

interdisciplinary team. This team consists of "insiders" (neonatologists that work at the unit under study) and "outsiders" (a psychologist/medical ethicist and a master student of public health). Different interpretations are discussed until a consensus about a shared interpretation is reached, which is a resource intensive interdisciplinary learning experience.

We are happy to give more insights into our study but also to learn more about our complex research top-ic. Please do not hesitate to contact us for more information, feedback, or questions.

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Syndromic surveillance for early detection and prevention of epidemics/pandemics:

The neglected role of the community-based pharmacist as a public health specialist

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ABSTRACT
Over the past decade, the developing world has experienced several infectious disease outbreaks such as Chikungunya, Zika and Viral Conjunctivitis and now the global pandemic of

Covid-19. These infectious conditions are of regional and global concern and not only affect a population at a point in time but have long-term effects. Long-term effects contribute to loss of productive time and present a burden for the already strained healthcare resources of low/middle-income countries. Of greatest concern is the spread of infectious disease due to globalization. COVID-19 has demonstrated how easily infectious diseases can be transported from one part of the world to another by a single traveler. It is for this reason that public health surveillance and notification measures are crucial in discussions about disease control. The crux of this paper is to examine the overlooked role of the pharmacist as a public health specialist and to posit that pharmacists, particularly community- based pharmacists should play a key role in public health surveillance, consequently contributing significantly to the fight against the global spread of disease.

Keywords: COVID-19, Pharmacist, role, public health, syndromic surveillance

INTRODUCTION

Public health surveillance is defined as "the continuous, systematic collection, analysis, and interpretation of health-related data for the planning, implementation, and evaluation of public health practice" (World Health Organization, 2017). One of the main purposes of surveillance is for early detection of impending public health emergencies. Early detection and mobilization of response are critical to prevent high death rates and the spread of infections (Groseclose & Buckeridge, 2017; World Health Organization, 2017). One of the main challenges to public health surveillance by physicians. Studies outlined the challenges physicians face due to lack of clarity on reporting procedures, tedious processes, exhaustive paperwork and lack of knowledge of reportable diseases [1]. This expectation of timely reporting is important as lack of information can cause a delay in the response by health officials. Physicians also complain that health facilities are understaffed and the physician to patient ratio is at times low [1]. One way to address the under-reporting by physicians is to encourage patient self-reporting. However, this is limited to those patients who had access to the internet and were aware of the process. Under-reporting is a major barrier to public health surveillance and can delay health interventions to prevent the spread of diseases [1]. Addressing this issue is important for any long-term public health intervention to be successful.

Criticism regarding recognizing, reporting and controlling the spread of infectious disease is however not limited to Low-middle-income Countries (LMICs), as this was also meted out to the world's largest public health organization, the World Health Organization (WHO) in its management of the Ebola disease outbreak [2] and now Covid-19. The Ebola outbreak resulted in over 28,000 reported cases and 11,000 deaths [2]. A panel of experts in its review of the outbreak in Ebola noted that the WHO was "slow in response", which was acknowledged by the WHO [2]. Consequently, a comprehensive review of the policies of the WHO was done and a global health security plan initiated [3]. The need to return to the fundamentals of a robust and responsive public health system which has community involvement was highlighted as well as the need to have greater cooperation regarding the implementation of the International Health Regulations (IHR) [3]. Reporting on epidemics by physicians is mandatory in law in many most countries, however, during an outbreak, community pharmacists may be the first to recognize this and perhaps are most exposed to the extent of the crisis. This assertion is based on the increased demand for pain and fever medication.

GLOBAL HEALTH SURVEILLANCE

The International Health Regulations

The International Health Regulations (IHR) is a global legal framework developed in 2005 and became binding in 2007 on the 196-member states of the United Nations [4] It requires member countries to report all outbreaks that may be of international/global public health concern [4]. It was discovered in the post-Ebola review that the IHR needed to be strengthened regarding practical approaches that are clear to all signatories, and oversight is needed to ensure the requirements of the IHR are met [5]. The WHO recognized that to effectively manage the spread of infectious diseases and ensure global health security, public health laws, systems and infrastructure of member countries needed to be strengthened [2], [5], [6]. Six actions were identified as necessary to ensure a strong public health system "(1) Revise public health law/policy framework, (2) Strengthen public health infrastructure: (a) Public health workforce, (b) Surveillance and information systems, (c) Laboratory capacity; (3) Build partnerships, (4) Use research evidence to inform decisions, (5) Engage and communicate with communities and (6) Establish a Public Health Emergency Operations Center" [3].

Ideally, in the quest for global health security an effective public health surveillance system should be "nationwide, interoperable, and interconnected platforms that can collect, aggregate, and analyze information at every level of the health system (community, district, other subnational, and national levels)" [3]. Surveillance is still considered one of the best strategy to control an epidemic while vaccination is noted as a key factor in controlling or eradicating diseases [3], [6]. However, for early detection and quicker mobilization of public health response to an impending epidemic, syndromic surveillance is identified as the key [6]. To facilitate comprehensive surveillance, syndromic as well as event-based surveillance would be necessary [7]. This system would have to be real time and transmittable to a central repository where the relevant health authorities can analyze the data and respond appropriately [8]. Syndromic surveillance is proffered as a convenient surveillance method to aid in the early detection of an outbreak especially in developing countries [9] and informs national surveillance systems of the number of reported or suspected cases reported [9].

Syndromic Surveillance

Syndromic surveillance, as defined by the Center for Disease Control, is "an investigational approach where health department staff, assisted by automated data acquisition and generation of statistical alerts, monitor disease indicators in real-time or near real-time to detect outbreaks of disease earlier than would otherwise be possible with traditional public health methods"[10]. Syndromic surveillance has been improved over the years and is a tool employed by the Center for Disease Control, the Canadian government, and in several other countries [6], [11]–[13]. The World Economic Forum in its report on Ebola and global health security highlighted that public health surveillance requires greater community participation and public-private cooperation [14]. This position supports the use of convenient and accessible methods such as those employed in syndromic surveillance to have earlier detection of outbreaks and better response to crises. Technology is key in this type of surveillance method and one commonly noted technological tool is the use of pharmacy-based software and over -the- counter drug (OTC) utilization [15].

There are several methods of data collection in syndromic surveillance, one of which is the use of

the pharmacy database. The database is connected to a central hub where spikes in drug utilization are monitored, and public health officials are alerted of a possible epidemic [11]. Community pharmacy based information systems are used in syndromic surveillance to identify influenza type and gastrointestinal infections based on OTC sales for items used to treat these infections [12] . Studies in France, Canada, and the USA have reported positive results for syndromic surveillance based on drug sales in Community pharmacies [8], [11], [13]. However, it is important to note that while syndromic surveillance can be an early indicator of an outbreak, there may be other factors that influence spikes in OTC drug utilization such as store initiated sales on certain products or seasonal purchases [16]. These types of purchases may trigger false alarms when fed back into a National database as was observed in New York. To avoid these false triggers, New York public health officials allowed alerts to go beyond two days or more, presenting a confounder to early detection, the main purpose of syndromic surveillance [16]. A possible approach to the challenges faced when using pharmacy databases may be to shift from database information to the actual pharmacists' involvement in the OTC drug purchases [17]. If actual sales are based on pharmacist recommendations, then a more accurate determination of an early outbreak could be done and would be based solely on an evaluation of symptoms of the patients [16]. Pharmacists are trained to identify and treat simple conditions such as the Common Cold, Diarrhea and gastrointestinal disorders [17], [18]. A community pharmacist is uniquely positioned as the first point of contact for patients who are experiencing the first set of symptoms related to a disease. Oftentimes if these symptoms resolve with self-medication or those recommended by the pharmacist, the patient may never go to a physician [19]–[21]. The Community pharmacy sales records and the pharmacist facilitate a huge public health opportunity for data [11], [12]. This has proven to be a good indicator of influenza type conditions [11]. One study while noting that syndromic surveillance yielded positive results in detecting disease revealed that it was not as sensitive to actual diagnosis as emergency room visits [22]. Another study in Japan and Great Britain indicated that OTC sales might not be a good indicator for every country [19] [23]. However, the differences noted in these countries could be based on the method of forecasting employed as was highlighted by Chretein et al. in a 2014 systematic review of studies on OTC sales correlation with influenza in various countries [24]. It is important to note here that pharmacists, particularly those in the community/retail settings, have the competency and data that can inform syndromic surveillance and assist in early detection of outbreaks but would not replace the diagnostic processes for disease confirmation by the health practitioner. The preceding studies revealed it would be ideal for pharmacists and doctors to be able to log the patient's information into a central database. This would prevent duplication should the patient progress to a worse state, and he/she visits the doctor for diagnosis. The physician's assessment and reporting on the same patient would support the pharmacist's preliminary assessment rather than a dual system. In other words, there needs to be a National Health information system where every patient is uniquely identified in the central database. It may then be important to identify the patient by a unique identifier number or identification that is supplied by a National Agency. This, however, may not be practical to employ in a low- income country hence alternative methods may be necessary. If syndromic surveillance is to play a significant role and be successful, community-based pharmacists could be engaged as part of a national public health strategic plan especially in low and middle-income countries.

The use of smartphones in syndromic surveillance has also been explored among health workers and actual patients in low and middle income countries and could be a useful reporting tool for pharmacists, especially if there is an application that would allow direct link to a central database [25]–[27]. This is ideal where there is no facility to permit community-based pharmacy computers to connect to a central database to analyze drug utilization for forecasting or identifying outbreaks. Pharmacists could use their smartphones to submit reports on the number of patients/clients presenting with similar ailments and to record identifying demographic information to assist in locating patients for follow up by public health workers [25]–[27].

A team-based approach towards surveillance

It is always ideal for the physician to be mandated to make reports as they are better able to diagnose conditions, however public health surveillance must be a team-based approach. The public health team should as much as possible include all healthcare workers. The traditional approach to surveillance would be the patient sees the physician who then makes an initial assessment followed by laboratory confirmation [28]. This formed the basis for suspected and confirmed cases. However, there is a natural lag which causes a delayed response as these are all time sensitive. Syndromic surveillance relies on symptoms and drug utilization for early detection and as such detects outbreaks quicker than the traditional method [28]. There could be a shift from reliance on physician reporting for confirmation of suspected cases and follow up to syndromic surveillance. The International Health Regulations requires every country to have a public health surveillance infrastructure in place [4]. If community pharmacist syndromic surveillance is to be given proper recognition, this would have to be done in law, where other health professionals have reporting duties, to ensure that pharmacists see it as part of their professional responsibilities. If pharmacists are incorporated in the public health team as multi-faceted resource personnel, the global health security agenda would be strengthened.

Community pharmacy-based testing and immunization programmes

Vaccination has been established as one of the most effective public health preventative measure since the first vaccine was discovered in 1796 by Edward Jenner [29]. Since then millions of lives are saved annually because of the administration of vaccines [29]. Vaccinations and the development of vaccines is a high priority for the prevention and eradication of highly infectious diseases [29]. Pharmacists have been recognized as uniquely positioned to improve access to vaccinations based on the number of stores and opening hours thereby providing convenience for persons who may need to be immunized [29], [30]. Countries across the world have now implemented both in legislation and practice and the results have been exceptionally positive [29]. The International Pharmaceutical Federation did a global survey in 2016 among 174-member organizations, resulting in 45 countries participating in the survey. Globally, countries reported pharmacy administered vaccination is legal in their countries or that there is some amount of advocacy for this to be done [29]. Majority of the countries, however, indicated that community pharmacies were an integral part of the education and promotion of vaccinations even if they were not allowed to administer the actual vaccines. Countries such as the USA, Portugal, and Australia have yielded very positive outcomes with the implementation of community pharmacy-based immunization programmes [29]. It was identified that high-income countries such as Canada and the USA had countrywide pharmacy-based programmes

while low/middle-income countries depended on doctors or other public health personnel [29]. It was highlighted however that pharmacy-based promotion of vaccination played an important role in the uptake of vaccines and as such supporting the role of expanding public health role of pharmacists especially in controlling and eradicating infectious diseases [29], [30].

SUMMARY AND RECOMMENDATIONS

Global Health Security is high on the agenda of the United Nations and subsequently the WHO. Following on the outbreaks of the past two decades, namely SARS, Swine flu, Zika, Chikunguyna, Ebola and most of all, Covid-19, the world has recognized that infectious diseases must be given high priority as a global issue as diseases are spreading much quicker now due to globalization. The WHO has put measures in place to bolster its responsiveness to because of the criticism of what was deemed its poor response to Ebola, however, there has been concern raised about its slow response to Ebola and Covid-19. Subsequently, global health priorities are focusing more on early detection, reporting and, response to an infectious disease of global concern. Member countries are expected to improve their public health infrastructure, systems and procedures to ensure compliance with the International Health Regulations. The issue of under-reporting by medical practitioners and slow response is a common challenge for many countries especially low /middle income countries. Although legal framework may be in place public health surveillance is stymied if the practical measures are impeded due to lack of human and other resources. Of the six actions proffered as essential for a strong public health system, the World Economic forum emphasized that public-private partnerships are critical in moving forward. This paper highlighted that community-based pharmacists can play a vital role in syndromic surveillance, dissemination of health information and immunization. Pharmacies are uniquely positioned in the communities that could feed the national surveillance- based on presenting symptoms and over the counter drug sales. Persons in most major outbreaks, including Covid-19 followed similar trends where the patients sought over the counter solutions for their symptoms at the pharmacies. Although syndromic surveillance has its limitations, it has been recognized as a method of early detection of outbreaks and can indicate the extent of the outbreaks. More studies need to be done with incorporating the use of mobile telephone applications as tools for direct reporting by pharmacists rather than self-reporting by patients or relying on traditional physician reporting. Research would also need to be conducted to identify the acceptability of this role by community pharmacists and other stakeholders. Pharmacists have long played vital public health roles in health promotion and immunization however there remains a knowledge gap on how well the role of the pharmacist, and not just information from the pharmacy database, can bolster public health strategies, particularly, syndromic surveillance.

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PhD Thesis: Addressing the Lack of Incentives for Data Sharing within Emerging Health Data Ecosystems

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Data infrastructures are being built to connect health data and transform the European health data landscape. In the long-term, these infrastructures are anticipated to be federated into the European Open Science Cloud (EOSC) and the European Health Data Space (EHDS) to enable efficient, cross-border sharing of data for research purposes, including with commercial companies. However, these efforts to facilitate data sharing cannot be reduced to their technical dimension. Many open science policy documents and academics have emphasized that our academic reward system disincentivizes researchers from engaging in open science practices, including data sharing (Ayris et al., 2018; Sim et al., 2020). From this perspective, data infrastructures may fall short of overcoming the lack of data sharing if they are not underpinned by sound science policy measures. Aside from discussions around due recognition, such policy measures touch upon many areas that (empirical) bioethicists have studied, such as procedures of data access and ethics committees and transparency obligations over data sharing.

Researchers might not prioritize data sharing because it is insufficiently beneficial for their careers. Data sharing for competing analyses puts future publication opportunity in jeopardy. Furthermore, in the absence of dedicated support for data sharing efforts, researchers are forced to allocate time to some activities at the expense of others. This is problematic as leading applied research projects is more professionally rewarding than contributing to the work of others (Devriendt et al., 2021). Contributions through data sharing often result in middle authorship, which is perceived to lack in value and to be particularly unsuitable for those that often make specialized contributions (e.g., methods, data…). Some researchers report being criticized by peers for engaging in data sharing, as they are perceived to be "contributors" rather than "leaders". Systemically sharing data upon request is argued to disproportionally affect junior researchers, as they dedicate most time to "invisible" labor, such as data production and management (Devriendt et al., 2022; Pinel, 2021). They do not benefit from being middle authors as they are expected to first-author publications to further their academic careers. In summary, credit and resource-related barriers are firmly entrenched into the functioning of academic reward and funding allocation systems.

Some academics have previously suggested that reciprocity could be an appropriate answer to stimulate data sharing through data infrastructures (i.e., those that contribute can reuse data). Nevertheless, this view falls short of addressing an inherent flaw in the academic reward system. Simply put, the reward system

has not been overhauled to reflect an increasing internal division of labor in research teams and institutions. For this reason, reciprocity does not address concerns over invisible and unrewarded labor nor over lack of resources; it merely reaffirms the notion that research data is an "asset" to be traded and rented out (Pinel, 2021). It also ignores that disincentives may exist for research institutions to promote data sharing by, for instance, investing in common data management units that streamline data management and sharing workflows. A comprehensive answer to the lack of incentives for sharing would be to embrace diversity in researcher's profiles by making evaluation systems role-specific. Among other things, this requires more focus on the types of contributions to research articles (i.e., data, software…) rather than the position of authors (Allen et al., 2019). Incentives for institutions can be altered by changing funding distribution keys or by allowing (partial) cost-recovery for data sharing through data management plans. In this way, those with "infrastructure" or "data production" profiles can be attributed and evaluated based on the broad reuse and professional management of research data. This creates the possibility to formally embed data sharing into the academic system by professionally rewarding data management and sharing, avoiding unrecognized labor and removing data as the bargaining chip for building careers.

Many funders of science in Europe have already embarked on this journey by introducing narrative review of CVs, where all types of outputs can be reported in narrative form instead of merely a list of co-authored publications. This initiative is also aimed at undoing the disproportionate focus on quantitative indicators of scientific productivity, which in the heads of many academics have become measures of success and targets to pursue. Nevertheless, narrative CVs have their own shortcomings if no further changes are made to attribution systems. For instance, claims in CVs may be completely unverifiable by reviewers, which is most problematic in hyper-competitive research fields. Cultural barriers need to be overcome to make use of the benefits that narrative review could offer. If researchers perceive they will be evaluated based only based on coauthored publications and quantitative indicators associated with their work, they will continue to tailor their CVs to accentuate these elements. In the coming years, it will be necessary to go through an iteration of policy changes and educational exercises to reappraise qualitative assessment of academic outputs.

A commonly asked question by researchers may be what evidence basis provides the justification for enacting all the aforementioned changes. A vicious cycle prevents answering this question meaningfully: There exists a lack of evidence to support implementation yet the lack of implementation prevents creating evidence. Data sharing platforms themselves can partly resolve this problem if they are designed to gather insights on data sharing that can be used to inform science policy development (Devriendt et al., 2020). From this perspective, platforms could be made into key instruments for evidence-based policy making as they are increasingly used to make health data findable, accessible, interoperable and reusable (FAIR) by research communities.

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New EACME Member: ETØK, University of Bergen, Norway

Kristine Bærøe

In 2021, the section Ethics and Health Economics (in Norwegian: Etikk og Helseøkonomi, ETØK) was welcomed as a full member of European Association of Centres of Medical Ethics (EACME). We are happy for this opportunity to present ourselves and to invite other members to get in contact with us.

The organisation of ETØK according to medical ethics is a bit on the complicated side. The short version of the story underscores that this is the section within the Department of Global Public Health and Primary care at the Medical Faculty, University of Bergen, which hosts those who are teaching and doing research on medical ethics.

The longer version emphasises that there are not only medical ethicists in this section. ETØK consists of two research groups: Bergen Centre of Ethics and Priority Setting (BCEPS) and Health Economics, Leadership and Translational Ethics Research (HELTER). The research groups are separated mostly for administrative reasons; they partly overlap in the research areas they cover and co-operate across administrative boundaries. For example, the groups arrange bi-

weekly PhD seminars together. ETØK's members have responsibility for teaching courses in clinical ethics, research ethics, health economics, philosophy of science and priority setting in health to students in medicine, health science, biomedicine and international health. ETØK is currently led by Professor Oddvar Kaarebøe.

In the following, we give a brief introduction of the two research groups, BCEPS and HELTER.

BCEPS is led by Director Ole Frithjof Norheim and Deputy Directors Ingrid Miljeteig and Kjell Arne Johansson. The BCEPS team at the University of Bergen comprises five professors/associate professors, one research coordinator, five senior postdoctoral researchers, and 14 PhD students. In addition, the centre has seven affiliated professors from international universities in part-time engagements.
BCEPS is an interdisciplinary research centre that aims to understand and promote ethically fair and efficient priority setting in health. The members develop and provide methods, evidence and normative guidance for ethically acceptable, fair and efficient priority setting for improved population health and well-being in national health systems. In addition, they provide decision support to countries for fair and efficient priority setting - on the path to Universal Health Coverage, for public health, and for intersectoral action - in partial fulfilment of the Sustainable Development Goals. For more information, please see the BCEPS website: www.uib.no/en/bceps.

The other research group, HELTER, is a recently established group led by Inger Lise Teig. HELTER comprises 4 professors/associate professors, and 5 affiliated professors/associate professors, and 6 PhD-students. The research group has three focus areas: health economics, leadership and health care service innovation, and translational ethics research. A major goal for the group is to perform disciplinary, multidisciplinary, and interdisciplinary research to promote better services, better health, and better welfare.

The members of HELTER carry out theoretical, qualitative, and quantitative research. Their research areas are translational ethics, fairness in priority setting, trust and power in healthcare, trustworthy Artificial Intelligence in health, social determinants of health, governing instruments of healthcare organization, economic evaluation, incentive theory, innovation and organization of health care, impact of contextual factors on clinical decisions, behavioral theory, intervention research, and empirical research on medical decision-making. For more information on HELTER and its members, please see: https://www.uib.no/en/globpub/139806/helter.

Both BCEPS and HELTER enjoy national and international collaboration with researchers within a broad scope of disciplines. A large share of the research portfolio takes place in low- and middle-Income countries.

Bioethical research in the ETØK section receives funding from the Trond Mohn Foundation, the Bill & Melinda Gates Foundation, the Norwegian Agency for Development Cooperation (NORAD), the Research Council of Norway, and the University of Bergen.

For more information about ETØK, please see: https://www.uib.no/en/etec.

We are truly grateful for being welcomed in EACME and we are looking very much forward to collaborating with the other members. If you have any questions regarding our activities, please do not hesitate to **contact Kristine Bærøe (Kristine.Baroe@uib.no) or Ingrid Miljeteig (Ingrid.Miljeteig@uib.no)**.

Book review

An ethics of compassion

Lazare Benaroyo

Soin et bioéthique - Réinventer la clinique

Paris: Presses universitaires de France, 2021, 106 p.

Médecin, Lazare Benaroyo a enseigné l'éthique et la philosophie de la médecine à Lausanne et d'autres universités (il a notamment publié "Ethique et responsabilité en médecine", 2006, et co-dirigé "La philosophie du soin", 2010). Le présent ouvrage est une présentation concise de ses positions, en particulier de ses réserves à l'endroit d'une éthique qui a trop accepté les conditions de la biomédecine actuelle, trop technique aux yeux du groupe d'auteurs dont il fait partie. "L'éthique clinique ne consiste pas seulement à prêter attention à l'individualité du 'cas' mais à la subjectivité de la personne" (...) La bioéthique compromet le primat de la relation interhumaine du soin."

Le premier chapitre est un utile résumé des origines de la bioéthique, depuis le Code de Nuremberg, puis l'avènement de la bioéthique nord-américaine. Le suivant discute les limites de cette dernière et de ses quatre grands principes - devenus des mantras avec, pour l'auteur, une dimension trop contractualiste. "L'autre pôle du soin, nourri par la souffrance d'autrui, qui mobilise une attitude d'écoute et de déprise de soi (du thérapeute) n'est pas pris en compte. » Le troisième développe sa vision, s'appuyant sur les positions de Paul Ricoeur et Emmanuel Levinas. Proposant une éthique de l'hospitalité et de la disponibilité, de la compassion aussi, dans le cadre d'une sagesse pratique (phronesis des Anciens). Un ouvrage intéressant et agréable à lire.

Jean Martin

Book review

About altruistic kidney donation

Qui veut mon rein ? -Enquête sur les donneurs altruistes by Francesca Sacco

CH-1225 Chêne-Bourg/Genève: RMS Editions, 2021, 215 pages.

Francesca Sacco, journaliste qui suit les questions de santé et médecine, se penche sur la problématique des donneurs altruistes, à savoir celles et ceux qui sont prêts à donner un rein à n'importe quel receveur compatible, au premier qui en a besoin, de manière non dirigée. Par solidarité humaine, pour lutter contre le manque d'organes, ou "pour avoir une fois fait quelque chose de bien dans sa vie".
La situation de plusieurs pays est décrite, avec des indications chiffrées. Le don altruiste est rare en Suisse (un ou deux par an). Il est interdit en

Allemagne. Ainsi qu'en France : on sait les positions restrictives dans ce pays liées à la non-patrimonialité du corps humain (dont des éléments ne sauraient être partie à des relations de type contractuel). Étant entendu par ailleurs que le don altruiste ne doit inclure aucun échange d'argent - en fait, ce point particulier est une raison de réserve/retenue (crainte de paiements cachés). Certains considèrent que ces donneurs, prêts à un geste "autosacrificiel", pourraient être des dérangés... Au long de l'ouvrage, les enjeux éthiques particuliers de ce don sont discutés, y compris avec un psychiatre.

Pour améliorer la qualité du matching entre donneur et receveur, les dons croisés de reins se sont beaucoup développés : au départ, entre deux paires de personnes qui ont des liens parentaux ou affectifs forts, mais où c'est le donneur de la paire A qui correspond le mieux au receveur de la paire B. Ce modèle a été élargi en mettant ensemble de multiples paires et des donneurs altruistes. D'abord aux USA puis ailleurs. F. Sacco décrit l'association israélienne Matnat Chaim dont elle a interviewé plusieurs membres.

L'auteure a suivi un compatriote suisse, Albert, candidat au don altruiste depuis 2013 et qui a eu périodiquement des examens de contrôle y relatifs. Les étapes de sa trajectoire sont décrites au cours de plusieurs entretiens et les dernières lignes du livre sont un échange avec lui au lendemain du prélèvement de son rein, en 2021 : " Le chirurgien est venu me trouver. L'équipe de transplantation est enchantée, le rein était parfait, la greffe a bien pris. Nous avons tous gagné". Des récits de donneurs altruistes d'autres pays sont présentés, avec leurs circonstances et motivations - et on trouve un chapitre "Portrait-robot du donneur altruiste".

Un ouvrage plein d'informations, agréable à lire, tout à fait intéressant pour qui suit les évolutions médicales et socio-éthiques.

Jean Martin

EACME Annual Conference 2022:

"Enhancing Dialogue to Bridge Gaps in Bioethics"

F. Nicoli, Alessandra A. Grossi, Elena Ferioli
Research Center for Clinical Ethics, University of Insubria, Varese, Italy

We look forward to seeing you at the University of Insubria (Varese, Italy), which will be hosting the upcoming 2022 EACME Annual Conference, dedicated to "Enhancing Dialogue to Bridge the Gaps in Bioethics", from September 15-17th, 2022.

Fifty years after the publication of the well-known book Bioethics: Bridge to the Future by Van Rensselaer Potter, and the foundation of the Kennedy Institute of Ethics in Washington DC, the 38th EACME Conference, organized by the Research Center for Clinical Ethics (CREC) of the University of Insubria, will address the theme of dialogue as a bridge to overriding gaps in bioethics.

The COVID-19 public health emergency has emphasized the emergent need for bioethical reflection. Yet, at the same time, it has shown how difficult it is for bioethicists to have a significant and effective influence on the public

debate. This reality prompts us to reflect on the very roots of our field, and to simultaneously address old and new challenges.

Topics and sub-themes

The conference will focus on four main topics and their related sub-themes:

a) The dialogue on bioethics: this topic deals with general reflections on theories and methodologies in bioethics, the role of bioethics in our pluralistic society, and the different approaches in bioethics. We also included the sub-topic "Bioethics Education", addressing not only education for health care professionals but also the need to raise awareness of bioethical issues in the general public. This sub-topic includes the following sub-themes: The relevance of theories and methodologies in medical ethics; Rethinking the role of bioethics after Covid-19; Religious and cultural pluralism in bioethics; Education and Awareness among healthcare professionals about bioethical issues; Beyond medical ethics: animals and environmental ethics.

b) The dialogue in clinical practice: the center hosting the EACME annual conference 2022 has always been interested in addressing ethical issues in clinical practice. With this topic, we would like to attract papers stressing on the importance of relationships in health care practice, and addressing the ethical issues inherent to a variety of sub-themes: Scope and limits of autonomy in clinical practice; Different methods in clinical ethics consultation; Ethics in organ transplantation; The influence of a clinical ethics service on moral distress; Ethics and the blurred line between clinical practice and research

c) The dialogue with society and politics: if we want bioethical reflection to influence public opinion, we also need to address the fascinating issue of its relationship with society and politics. With this in mind, we would like to attract papers concerning fairness and justice in health care, the role of mass media, and that of social media. This topic includes the following sub-themes: The dialogue between ethics, deontology, and law; The role of bioethics in national and international political decisions; Justice, solidarity, and equity in health care; Public opinion and media; Global bioethics and local bioethics.

d) The dialogue regarding the future: new and emerging technologies. With this last topic, we want to attract papers investigating the ethical issues arising from the implementation of new technologies in medicine. This topic includes the following sub-themes: Gen-Ethics: Genetic tests, Gene Therapy, Biobank; Robo-Ethics, Nano-ethics, Public Health 4.0 and High-Tech Medicine; Neuro-Ethics: Neurolaw, cognitive sciences, free will and moral cognition; Digital medicine: big data, and privacy; Bio-security and biological threats.

Location and abstract submission norms

The conference will be held at the University of Insubria - Monte Generoso Building in Monte Generoso n. 71, 21100 Varese, Italy.

The abstract submission deadline has been extended to Monday, May 2nd, 2022.

The Abstract Submission Form remains unchanged and must include:

- Authors (main presenter and guests), their academic Institutions and status therein.
- Email address
- Title
- Conference topic and subtheme (if applicable)
- Type of presentation: oral or poster presentation
- Text of the abstract (350 words max, no abbreviations, no references)

The Abstract submission form and registration

information are available on the conference website https://eacme2022.it.. For scientific-related inquiries please contact crec.secretary@uninsubria.it, and for abstract, logistics and organizational inquiries please contact info@summeet.it.

The Plenary sessions will be structured by Key lectures, including debates and a round table.
The confirmed Keynote speakers are:
- **Laura Palazzani**: Full Professor of Philosophy of Law in LUMSA University, Rome, Italy;
- **Gerald Neitzke**: Professor at the Institute of Ethics, History and Philosophy of Medicine, Medizinische Hochschule, Hannover, Germany;
- **Massimo Cardillo**: General Director of the Italian National Transplant Centre, Italy;
- **Veronique Fournier**: Founder of the Centre d'éthique clinique, Hopitaux de Paris, France;
- **Ana Boroveski**: Professor and the Chair of the Department of Social Medicine and Organisation of Healthcare at Andrija Stampar School of Public Health, School of Medicine, University of Zagreb, Croatia;
- **Marianne Boenink**: Professor in Ethics of Healthcare at the Radboud University Medical Centre in Nijmegen, the Netherlands;
- **Davide Battisti**: Research Fellow at the Center for Clinical Ethics, University of Insubria, Italy and adjunct professor of Bioethics at the University of Milan/Vita-Salute San Raffaele University, Milan, Italy;
- **Massimo Reichlin**: Full Professor of Moral Philosophy at the Faculty of Philosophy, Vita-Salute San Raffaele University in Milan, Italy.

The Scientific Committes is composed by Mario Picozzi (President of the Conference), Ruth Horn, (EACME President) Federico Nicoli (EACME Treasurer, CREC member), Bert Molewijk (EACME General Secretary), and Alessandra A. Grossi (CREC member). The Organizing Committee is composed by Elena Ferioli (CREC member); Silvia Siano (CREC member), Giulio Corgatelli (CREC member) and Anna Emanuela Costanzo (CREC member).

We look forward to welcoming you in Varese!

ECEN Open Forum Day

Save the date: ECEN OPEN FORUM DAY (Wednesday 14th of September in Varese, Italy)

Like every year, the European Clinical Ethics Network (ECEN) organizes an ECEN Open Forum Day for everybody interested in practice, training, implementation and evaluation of clinical ethics support services (CESS). This year it will be on Wednesday the 14th of September in Varese, prior to the EACME conference.

Although various CESS topics will be discussed, a central theme will be patient, parents and family participation in CESS. The call for abstracts and the preliminary program will soon get published on the ECEN website: www.ecenetwork.org
Those interested to present and share their work, please send an email to: neitzke.gerald@mh-hannover.de (member of the ECEN Steering Group).
We hope to see you there!

Best wishes, on behalf of the ECEN Steering Goup
Bert Molewijk (professor Clinical Ethics Support)
Chair ECEN Steering Group

Early Career Researchers in Bioethics: Call for Expressios of Interest

Call for Expressions of Interest

• Are you an early career researcher (e.g. PhD candidate) working in the field of bioethics?
• Would you like to meet with other early career colleagues from across Europe?

Early career researchers are the future. This is true of all academic fields of research, including the broad field of bioethics.

EACME has long endeavoured to support early career researchers, including through its conference and other activities. EACME recognises that, in these pandemic years, early career researchers will have had fresh challenges to overcome, less chance to present and discuss their work, and also fewer opportunities simply to meet and talk with their colleagues, both in their home country and around the world.

We are delighted that there will be such opportunities at our forthcoming **conference in Varese** this coming September. However, we also appreciate that not everyone will be able to attend – and that September is some months away! EACME therefore proposes to host an online meeting this June for early career researchers.

Would you like to take part in an online meeting of early career researchers in bioethics?

We expect to run this first webinar/meeting in approx. June. We will confirm the date after we have heard from people who are interested in taking part.

We will finalise the details in the near future, but anticipate the meeting will last up to two hours and is likely to include:

• The opportunity to meet with colleagues from EACME centres;
• For those who wish to do so, the chance to briefly present what you are working on;
• Discussion of areas of shared interest and common challenges encountered, not least during the pandemic and other challenging global events;
• Discussion of further ways that EACME, and its broad network, might be able to further support early career researchers in bioethics.

We currently anticipate running one virtual meeting in the coming months but, if there is sufficient demand, we would be happy to explore the option of running future events or other initiatives.

Who is hosting the meeting?
This first proposed webinar/meeting will be hosted by colleagues at the Centre for Ethics in Medicine, University of Bristol, UK, with input from other EACME colleagues. The Bristol Centre has a thriving postgraduate research culture: it will be hosting the UK's Postgraduate Bioethics Conference this coming July (details **here**), and is currently running a project, **BRIDGES:BKY**, with colleagues in Japan and Korea, which is focused on early career researchers in bioethics. The Bristol organisers of this meeting are Dani O'Connor and Richard Huxtable.

Who can take part in the meeting?
We are keen to meet with early career researchers who are working in the broad field of bioethics. This includes researchers working on bioethical questions in such disciplines as philosophy, the health sciences, the social sciences, law, theology, and many others. You may be undertaking a postgraduate course (such as an MSc, MA or PhD) or may have recently started in a position (for example, as a lecturer or post-doctoral researcher). We are not presently adding any strict requirements about the length of time you have been working or studying in the field. If you are interested, and consider yourself to be an early career researcher in bioethics, please register your interest (below).

How do I register my interest in taking part?
If you are interested in principle in joining such a webinar/meeting, please register your interest using the following MS Form: **here.** (This form will capture basic contact and geographical information, plus a little information about your areas of interest – we will currently only use this information to organise the webinar). Please aim to register your interest by or on Friday 13 May.

What language will the meeting use?
This meeting will be conducted in English. We are unfortunately not able to offer translation support at this meeting. However, we are open to exploring the possibility of future meetings in other languages, or with translation support, which would enable us to hear from more researchers from EACME centres.

Who do I contact if I have questions?
Please use the MS Form (in the link above) to contact us and ask any questions you might have, but, if you prefer, please feel free to email Dani O'Connor: do17934@bristol.ac.uk

Thank you for your interest and we look forward to connecting with you!

Fall School – Bioethics *in* society:

The challenges of a complicated but necessary relationship

*From the **10th to the 14th of October 2022** in Como (IT), the Research Center for Clinical Ethics, University of Insubria, will host the fall school "Bioethics in society" in order to investigate the role of bioethical reflection in nowadays society.*

During the Covid-19 pandemic, we have observed an increasing interest, within the public discourse, on many ethically relevant issues, such as the allocation of health care resources in emergency contexts, the substantial limitation of personal rights for the collective well-being, the allocation of vaccines, the communication of medical and scientific information to the lay public, and disagreement among experts. While, on the one hand, the emergence of these issues has underlined the need for bioethical reflection in our society, along with the conceptual tools to address complex ethical issues, on the other hand, this phenomenon has highlighted how difficult it is for bioethicists to effectively contribute to collective decisions.

People struggle to conceive bioethics as a practical discipline and to understand its real usefulness. Nowadays, bioethics remains mainly an academic subject confined to theoretical reflection; however, this seems to be in contrast

with the very meaning of bioethics which, since its foundation, has aimed to provide practical tools for personal and collective decisions related to the challenges of medicine and scientific progress. In the light of this scenario, there is a need to think about bioethics and its (putative) role in nowadays society.

The Research Center for Clinical Ethics (CREC) of the University of Insubria, would like to invite to participate in a fall school to deal with the aforementioned questions.

More specifically, the school is structured as follows. After an introductory class on the role that bioethical reflection should theoretically play in society, we will offer classes to address what bioethics currently is and the relationship between bioethics and other disciplines such as medicine, law, and politics. These analyses are important for understanding the role and spaces that bioethical reflections – should – have in practical contexts such as clinical practice, ethics committees, and policy-making.

Second, we will address the role of bioethics and the influence of bioethical reflection across different countries including the United States, the United Kingdom, Belgium, and Italy. By doing so, participants will be able to appreciate similarities and differences among different countries, to grasp how bioethics should deal with the pluralism of values in contemporary societies, and the relationship between bioethics and public and private institutions.

Finally, we will propose a final reflection on the future perspectives of the relationship between society and bioethics, trying to identify the necessary steps to enhance the practical role of ethical and bioethical reflection. Aside from keynote lectures (two per day), we will propose group activities and discussion of the participants' papers.

Where and When

The school will take place in person, in **Villa del Grumello**, via per Cernobbio, 11 – Como, Italy and will last five days, from **10th to 14th of October 2022**.

Keynote speakers

- **Arthur Caplan** (online), Professor of Bioethics, NYU Grossman School of Medicine, USA.
- **Chris Gastmans**, Professor of Bioethics, KU Leuven, BE.
- **Francesca Minerva**, Assistant Professor of Bioethics, University of Milan, IT.
- **Giulia Cavaliere**, Lecturer in Medical Law and Ethics, King's College, London, UK.
- **Massimo Reichlin**, Professor of Bioethics and Moral Philosophy, Vita-Salute San Raffaele University, Milan, IT.
- **Richard Ashcroft**, Professor of Bioethics, Queen Mary University of London, UK.
- **Stefano Semplici**, Professor of Social Ethics and Bioethics, University of Rome "Tor Vergata", IT.

How to apply and call for abstracts

Prospective participants have to fill out and submit the form on https://bios.lakecomoschool.org/, and upload a CV and a motivation letter.

We also invite participants to submit papers concerning the topics that will be discussed during the "Bioethics in Society" School. Papers dealing with bioethical issues that have or can have a huge impact on society are also warmly welcome. For example, we look for contributions that address ethical, social, or regulatory issues in the following broad topics:

- Philosophical reflection in bioethics
- Moral, cultural, and religious pluralism
- Bioethics and education
- Ethics, policy, and law
- New technologies & their impact on society

- Bioethics and mass media
- People attitudes toward bioethical issues and bioethics
- Bioethical expertise

Abstracts (no more than 350 words) should be submitted by the **30th of May 2022 (deadline extended)** on https://bios.lakecomoschool.org/. Presentations will be 20 minutes (including Q&A) and will be held in person, barring any future restrictions due to the pandemic. Note that submitting **an abstract is not required to attend the school.**

For other information regarding registration and fees, please visit our https://bios.lakecomoschool.org/ or write to davide.battisti@uninsubria.it

Davide Battisti & Mario Picozzi,
co-directors of the Fall School

International Neuroethics Conference

Annual Meeting, 2-4 Nov 2022, Montréal, Canada (hybrid)
Call for abstracts until 31 May 2022

The 2022 Annual Meeting of the International Neuroethics Society (INS) on November 2-4 will be a hybrid event and include opportunities to participate online as well as in-person at the Montreal Clinical Research Institute (IRCM) in Montreal, Canada.

The theme is: 'Bringing Neuroethics to Life Throughout Patient Care, Research, and Policy.' Main sessions of the program will focus on topics such as: prevention; diagnosis; emerging therapies, technologies, and research; and neurorecovery and end of life.
Researchers and clinicians from around the world can present their work and scholarship related to the field of neuroethics as a poster or talk. See the call for abstracts for complete details about this opportunity available to investigators at all career stages.

The INS Annual Meeting is a scientific conference for students, scholars, and professionals with an interest in neuroethics and the ethical, legal and social issues related to advances in brain science.

The INS especially encourages participation and welcomes abstracts from our colleagues from marginalized groups and/or with perspectives that are underrepresented in the field — including women, people identifying as LGBTQIA+, people with disabilities, and investigators working in or originating from Africa, Central and South America, and Southeast Asia.

- Call for abstracts: https://www.neuroethicssociety.org/2022-annual-meeting-call
- Website: https://www.neuroethicssociety.org/2022-annual-meeting
- Theme: https://www.neuroethicssociety.org/2022-annual-meeting-theme
- Email signup: https://www.neuroethicssociety.org/2022-annual-meeting#signup

Ralf Jox, INS Member and Ambassador of the 2022 Meeting

DEADLINE NEXT NEWSLETTER

The deadline for the second edition of 2022 is:

September 1st, 2022

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

Please get in touch and do not hesitate to contact our editor Caroline Brall:
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