

# EACME Newsletter

European Association of Centres of Medical Ethics

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## EDITORIAL

Dear EACME colleagues and friends,

The recent legal case of a child whose parents sought innovative treatment for his serious genetic disorder, Charlie Gard, has meant that medical ethics led the news in the United Kingdom for a number of weeks.<sup>1</sup> Owing to interventions from public figures internationally, these debates, like those centred on Eluana Englaro and Terri Schiavo in the past, have been aired in the international media. As the courts deliberated, the media reports have been accompanied by a widespread public engagement through the internet and social media, as well as mobilisations of interested groups who hoped to influence decision-makers. While some of these interventions were reasoned and thoughtful, much intervention was passionate. Indeed, professionals at the treating hospital were subject to threats of violence and worse. At the same time, the media were hungry for the views of bioethicists and scientists and many in the U.K. were approached to speak, write or debate. Many were in a quandary – was it disrespectful to express a view on a private matter whose facts were not fully known? Or instead, were the moral issues so urgent and important that we had a duty to contribute despite our ignorance? Equally, there were personal dilemmas - did we as individuals want to publicly express views on a matter when public feeling ran so high? So, we all had a chance to think hard about exactly what it meant to be medical ethicists.

The case and its developments touched on central debates within bioethics: At what stage does an experimental treatment become research? Should deciding for children be left to professionals or should families be empowered? Should medical ethics be about democracy and the views of the public, or does this invite serious moral misjudgements? These are

important issues and touch upon many of the themes of the upcoming 2017 EACME conference in Barcelona, which is centred upon “Justice in Health Care – Values in Conflict”. In this issue of the newsletter we carry a short paper on this theme, discussing the value conflicts raised by attempting to ensure justice while protecting vulnerability. It make interesting reading and I am grateful to the contributor for sharing such fine work with us. Other pieces in this newsletter showcase the diversity of ethical debate in other areas, such as the place of spirituality in end of life treatment, the work of national ethics committees and the intersection of the law and medical ethics. I hope then, that this newsletter can whet your appetite for discussion of these important issues, and look forward to meeting some of you in Barcelona to do just that.

Giles Birchley, Editor

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1. Guardian, Monday 24<sup>th</sup> July. <https://www.theguardian.com/uk-news/2017/jul/24/charlie-gard-parents-end-legal-fight-over-critically-ill-baby>

## CLINICAL ETHICS CONSULTATION IN A SWISS PSYCHIATRIC UNIVERSITY HOSPITAL: MULTIPLICITY AND DIVERSITY

### Research Fellowship in Clinical Ethics Basel

Since my participation (2012/13) in a course program on Clinical Ethics Consultation at the Cekib in Nürnberg (FLG)<sup>1</sup> I became quite interested in the work of Professor Stella Reiter-Theil and her team in Basel/Switzerland. Working as a psychological supervisor in psychiatric hospitals and teaching management students at a nursing science department, Zwickau University of Applied Sciences (East Germany), I developed interest in ethical problems brought forward to Clinical Ethics Consultation in Psychiatry. Moreover, I was keen to learn about the implementation processes and structures of Clinical Ethics Support to be found on a quite advanced level at the University Hospital Basel (USB) and the Psychiatric University Hospitals (UPK) in Basel. Supported by the West-Saxonian University of Zwickau permitting me a research semester, I spent more than two months between November 2016 and February 2017 as a research fellow in the Department of Clinical Ethics in Basel.<sup>2</sup>

<sup>1</sup> (FLG) Fernlehrgang Berater/in für Ethik im Gesundheitswesen

<sup>2</sup> More information about the hosting institution: <http://klinische-ethik.unispital-basel.ch>;

I could not only participate in ethics consultations taking place in Psychiatry during this period, but also in different forms of Ethics Education for doctors, nurses, students and managers, seminars for PhD students and a European colloquium on research of clinical ethics support with colleagues from Britain, Italy, Netherlands, Norway and Romania. My main interest was to work with the Basel Data Base of Ethics Consultation<sup>3</sup> of more than 130 systematically documented ethics consultations including more than 50 cases from Psychiatry. By analyzing the data, especially the records from psychiatric ethics consultations, we continued the comparison of similarities and differences of Ethics Consultation that I had started (as my take home assignment of the FLG course) and that has been followed up since.<sup>4</sup> We wrote a paper presenting a systematic comparison of both approaches and our conclusions.<sup>5</sup> A second paper will focus on the role of nurses in (requesting) ethics consultations: which questions and problems are put forward by (leading) nurses and which content matters of ethics consultations in general refer to ethical issues of nursing? One important question in this realm is how far ethics support can contribute to reducing or even preventing moral distress among hospital staff.

Not just talking about the products of my stay in Basel, I really liked the inspiring and intense discussion with Stella and her interdisciplinary team, everybody working on his or her own questions, papers, case documentation, but in a manner of staying connected during the permanent process to improve one's precision in using theoretical concepts and responding appropriately to the problems and questions raised in clinical practice in order to provide a helpful service. There has also been a considerable number of (leading) doctors and nurses as well as managers, in more or less continuous contact with the ethics department, who really support the development of Ethics in these university hospitals, and with whom we had a lot of interesting discussions: e.g. on the role of relatives in ethically difficult decisions especially in geriatrics or in child psychiatry, patient decisional capacity, practice of coercion or questions of fairness in the treatment of migrant patients.

Last, but not least it should be mentioned (for a person

<http://www.upkbs.ch/patienten/ethik/klinische-ethik/Seiten/default.aspx>

<sup>3</sup> Reiter-Theil S, Schürmann J (2016) The 'Big Five' in 100 Clinical Ethics Consultation Cases. Evaluating three years of ethics support in the Basel University Hospitals. *Bioethica Forum* 9(2): 12-22

<sup>4</sup> Mitzscherlich B (2014) Ethische Konflikte in der Psychiatrie als Thema der Supervision. *Psych Praxis*; 41(07): 379-384; Anonymous (2016) Ethics consultation in the context of psychological supervision: A case study. *Clin Ethics* 11(2-3): 97-104

<sup>5</sup> Mitzscherlich B, Reiter-Theil (2017/in Druck) Ethikkonsultation oder psychologische Supervision? Kasuistische und methodische Reflexionen zu einem ungeklärten Verhältnis. *Ethik Med*

like me who is not used to Swiss style organizations, but rather experienced in a more Eastern European (Kafka-like) type of university bureaucracy) how easy it was for me, just to start working. That means that I had to spend less than 30 minutes of my first working day to inscribe, receive a key and a badge and be able to use all the given research infrastructure (including the Data Base) and get access to literature. I hope that this cooperation will continue.

My message to the readers would be: everybody interested in doing research on a Clinical Ethics theme, especially researchers with an interest in relating their own ethics consultation data to others, can be advised not to miss the chance of an exchange with the Basel Department of Clinical Ethics, because this collaboration might really qualify your work.

(Still I could say a lot about the Rhine, the museums and art galleries in Basel, the high level on which contemporary and old baroque music is performed ..., but this is just the icing on the cake.)

Acknowledgements: I am very grateful to Stella Reiter-Theil, her colleagues and the Human Resources of the Psychiatric University Hospitals Basel, allowing me a most fruitful research semester.

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## JUSTICE, VULNERABILITY AND DEVELOPING A MALARIA VACCINE

To be vulnerable means to be susceptible to being wounded, stemming from the Latin word *vulnus* – wound. In this sense, all physical beings are vulnerable. Such an ontological approach can evoke a kind of visceral camaraderie amongst us upright walkers, which can be helpful when looking at issues concerning global health research. What underwrites all global health work is this recognition of a common humanity, bringing us together in solidarity. And if we build on this approach, the principle of justice calls on us to work towards reducing the burden of disease in the developing world through increasing access to interventions and developing new methods to do so; both of which require resources from high-income countries and donor organisations.<sup>1</sup> *Inter alia*, it requires us to share the burden of disease and conduct vigilant research committed to the well-being of local people, preventing further impoverishment of the families and communities. This is complex work and moves us along a tight rope to adhere to the principle of justice and protection of vulnerable

participants, without reducing the principle of autonomy.

In recent years there has been accelerated investment in the push for the development of a malaria vaccine. In response to this movement, questions surface around justice and the vulnerability of the research participants and intended benefactors. Recently, through a public-private partnership with PATH Malaria Vaccine Initiative (MVI) and GlaxoSmithKline (GSK), a malaria vaccine candidate targeting children received positive reviews from European regulators and was approved by the WHO for implementation in a wide-scale pilot-study set to begin in 2018. RTS,S is a vaccine effective at cutting severe malaria disease by one third. This is significant in terms of mortality and morbidity when the sheer number of individuals affected by the parasite is factored in; however, in contrast to other childhood vaccines, the efficacy is low. The complex ethical concerns around the risk of exploitation in these vulnerable populations, a favourable risk-benefit ratio, and justice are left to be explored. As the malaria vaccine transitions out of clinical trials and into pilot studies in 2018, the needs of the local communities must be balanced with the wishes of the researchers.<sup>2</sup>

Research in low-resource settings faces terrain very different from that of high-income countries. In many cases it is difficult for vaccine developers, whose chins are comfortably raised above the poverty line, to understand this terrain. The extent to which a research participant is gripped by poverty will play into the likelihood of consenting to an unfair benefit:risk ratio. Consenting to such an exploitative transaction may happen when the researchers benefits and the participant is harmed, or both benefit but there is not a just distribution of the benefits.<sup>3</sup> To contextualize it in the RTS,S vaccine paradigm, mothers may not have access to health care and consenting to a vaccine trial, regardless of the risks or conditions, may be the only feasible method to access medical care. Furthermore, the financial incentives around participation may provide a much-needed economic boost for the participant's family, thereby inducing enrollment and reducing voluntariness of participation. To adequately address this, researchers should move beyond international guidelines from the Council for International Organizations of Medical Sciences (CIOMS) or the Declaration of Helsinki (DoH), to develop more context-sensitive approaches to mitigate the risk of exploitative research in the malaria vaccine development context. One effective way to do this is by reaching deeper into the pools of local community knowledge to understand the contextual factors contributing to vulnerable circumstances. In the Sub-Saharan African setting of RTS,S and with children being enrolled, the development of this vaccine creates

a milieu where participants are at risk of being exploited because they are vulnerable. Discrepancies in power, education, and resources all exasperate the vulnerability and call for diligent approaches to mitigate the risk of this occurring.

If our aim is to understand and address the multifaceted tapestry of vulnerability, without reducing one's right to self-determination, we first must acknowledge how individual circumstance weaves itself into research studies designed to reduce the global malaria burden. The degree of vulnerability is dependent on both the time and space each individual participant occupies. That same individual may not be vulnerable in all moments of time and in all contexts. This fluidity bids us to carefully consider the realities individual research participants inhabit. The interplay between different players in the vaccine development process, field dynamics and power relations are confounding factors that contribute to the degree of vulnerability of an individual participant.

The failure to talk frankly about the implications of education, standards of care, inducement and power discrepancies would be regrettable for the global health field as a whole. By critically calling into question each of these aspects when developing new interventions, we can inspire deeper questions around justice and vulnerability for all clinical research studies in low-resource settings. The RTS,S malaria vaccine project, alongside numerous others striving towards a reduction in the global disease burden, has strict guidelines around protection of its vulnerable participants and adheres to high standards of ethical conduct. However, these robust standards that are applied across the world, as defined by the international community, may not adequately address the context-dependent concept of vulnerability. Instead they have the potential to drop us further into a paternalistic puddle disconnected from the humanity on the receiving end. The main driver that will finally help us hit a tipping point after years of steady, if lukewarm, improvement will be more meaningful exchanges with community members. These exchanges need to take place across the board, between those on the lower rungs of the power ladder and those well above. Gaining insight into the realities participants inhabit is essential for conducting ethical research in a just and fair manner and will have us asking deeper questions around vulnerability and justice. And the time to start discovering those questions is now.

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## TOP FOUR ETHICAL ISSUES IN THE HEALTHCARE SYSTEM IN ROMANIA

Lately, mass media in Romania are more and more focused in the relationship physicians and patients and cases that illustrate bad medical practices. Practices used and perpetuated for decades are denounced by patients, caregivers or healthcare professionals on social networks and media. Extreme cases are currently shown on television or commented on social networks. These cases generate fear in population concerning medical acts and the physicians' behavior. Patients fear being not treated properly, family members/caregivers sue doctors in the courts, while physicians live and work under the rule of fear, doubt and confusion. It seems like we are in war, everyone has something against all others.

### How the study was conducted?

This study is the result of discussions with three groups of residents (cardiologists, oncologists, and radiologists), during their training in bioethics, as focus groups. The purpose of the focus group was to delineate the most common issues in the health care system in Romania, from their point of view. They were asked even about causes and generating factors of these issues, and also to imagine possible solutions to eliminate or diminish conflicts and to avoid ethical issues or medical malpractices. The justification for choosing residents rather than senior medical doctors or community members is that they seem to be more neutral than senior medical doctors involved in clinical cases and difficult situation. Participants are not directly involved decisions, but they have a good familiarity with day to-day problems and challenges of health care system in Romania.

Residents were at the end of their training, in the last two weeks, being already specialists. They were chosen for two reasons: 1) for their experience in medical practice; 2) because they are the largest groups of residents (around 25). We believe that due to their experience and also the fact that in a couple of

weeks they will make their own decisions and assume their responsibilities, these groups would be able to provide a wide and informed perspective on the ethical issues in the health care system in Romania, causes and possible solutions.

We started the study by developing questions on the topic and the script. The purpose of the study is to find out the perception of young medical doctors on the ethical issues of health care system in Romania and possible solutions. We developed four general questions on identifying: the ethical issues currently experiencing in medical practice in the health care settings in Romania; the main causes behind these issues; someone / something that generates or perpetuates these causes; and how to remove causes of these issues.

Each group of residents came to the meeting with their colleagues in the same medical specialty. There were three different sessions, with: cardiologists, oncologists, and radiologists. They were asked to provide answers to questions of what they believed to be the ethical issues in the health care system in Romania, in their own words. In this context the phrase “ethical issues in the health system” was meant to imply difficult situations, confusions, misinterpretations related to ethics and would have consequences for patients directly or indirectly. Participants responded orally to questions, by introducing new ideas or deep their colleagues’ answers, or provide examples in order to illustrate ethical issues.

The whole session was recorded. After that, we transcribed the registration and made the list of all issues highlighted by the participants. A list of 10 issues and related causes was identified by participants from all groups. We select four of these issues that were most mentioned and debated during the meetings.

**Discussion**

The four most highlight ethical issues resulted by focus groups are listed in Table 1. The most debated one was the problem of trust: trust in medical doctors, in medical acts, and in health care system, generally speaking. The lack of trust is due to the acts of corruption massively denounced by the media and on social networks. It also occurs because physicians treat patients in a very paternalistic way, talking mostly with family members and rarely with patients.

**Table 1: Top Four Ethical Issues in Healthcare System in Romania**

Rank	Scenario
1	Lack of the <b>trust</b> of patients in physicians and in the health care system;
2	Lack of <b>information</b> to patients in order to obtain informed consent to medical treatments;
3	Lack of <b>communication</b> between professionals / Under-financing of the health system;
4	Lack of clinical practice <b>guidelines</b> .

The second issue related to the first one, is the lack of information and communication with patients, about what is important to know about the medical act, risks, consequences, side effects, alternatives, costs. Usually, physicians complain that they do not have necessary time to provide all information about medical interventions, and also they do not verify if patients understood the information in a properly way. In addition, Informed Consent forms are not drafted in a properly way, in the most part of situations, physicians do not have proofs that they provide patients with appropriate information in order to obtain the informed consent to medical interventions.

In the third place, participants ranked the lack of communication between professionals, between physicians from different specialties. This situation can harm patients. And professionals involved in the medical act could be subjects of medical errors or malpractice. Also, scarce resources within the health care system are listed as the third ethical issue and not the first one. This is quite surprising, coming from residents because, usually, when physicians defend themselves in case of malpractice, this is the first reason they mention if they fail medical procedures. And in the majority of situations this is true.

As the fourth ethical issue, young physicians think that the lack of guidelines for clinical practice is the reason for confusions and misinterpretations in the healthcare system in Romania. They consider that clinical practice needs to be uniform in all settings, on different medical specialties. So far, there are only in few procedures and they consider that medical errors and malpractice could be avoided if they follow the same practices.

**Concluding remarks**

This paper is only the first step of an exhaustive study on ethical issues of health care system in Romania. The purpose was to list the most known ethical issues raised in the last years in Romania health care system. The rank of issues is coming only from young physicians’ perspectives and, perhaps, more experienced medical doctors could have other opinions. The study will be continued with more participants in order to can have a wide range of

opinions, motivations and possible solutions. As a conclusion, in order to improve health care system and to avoid medical malpractice, young physicians propose the following solutions: eliminate the acts of corruption, more transparency and communication, legal regulations and clinical practice guidelines. These changes need to be a high priority for the health care professionals in Romania.

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## LE TRAVAIL D'UNE COMMISSION NATIONALE D'ÉTHIQUE

### Un regard des Etats-Unis

Au numéro 3/2017 du *Hastings Center Report* est joint un Rapport Spécial traitant des Commissions nationales d'éthique. On se souvient que le pionnier en la matière est le Comité consultatif national français (CCNE), créé en 1983. Membre de la Commission nationale suisse (CNE) de 2001 à 2013, j'ai été intéressé par ce document, notamment le texte de l'éthicien Alexander Capron, de l'University of Southern California (1), qui discute le statut et les activités des sept commissions officielles qu'ont connues les USA (nommées par le Congrès ou le Président) depuis 1974.

**Membres, durée des mandats.** Dès la première, ses membres étaient issus d'une diversité de domaines. De plus, ils n'étaient/ne sont pas supposés être des représentants, des avocats corporatistes, du milieu dont ils émanent. Pour Capron, il importe que cela reste la règle. Il est judicieux aussi que, comme jusqu'ici, les serviteurs publics (de l'administration fédérale) ne puissent être membres. La commission doit être un groupe varié de personnalités réfléchies capables de délibérer constructivement et d'arriver à des conclusions d'une façon qui répond aux besoins de la société. A son avis, son mandat ne devrait pas être limité dans le temps (la continuité est une condition du succès), mais bien celui de ses membres.

**Mode de fonctionnement, transparence, rapports.** Il importe que des organismes chargés de conseiller l'autorité fassent de l'éthique en public, dit Capron - condition salubre parce que le fait de parler « on the record » (avec un enregistrement accessible) incite à être bien attentifs à l'exactitude et la pertinence de ce qu'on affirme. Rendre publics ces travaux est bien entendu beaucoup facilité par internet, qui fournit aussi

la possibilité de feedback par la collectivité. Note de J.M. : j'ai parfois été ambivalent quant à cette exigence de « publicité ». Oui, on est alors plus prudent dans ce qu'on dit mais cela peut enlever un certain caractère vif, voire provocant, aux débats.

Pratiquement, les Commissions américaines ont fonctionné de manière inductive, étudiant les questions dans leur contexte spécifique. Ceci plutôt que de vouloir articuler a priori un cadre de grands principes généraux. A une exception près, les travaux de ces commissions ont montré une forte tendance à rechercher le consensus. Capron : « Le seul vrai pouvoir d'une commission - le pouvoir de persuasion - est plus fort s'il y a unanimité. »

« Les rapports de commission doivent être intellectuellement respectables, dit-il, mais leur audience prioritaire n'est pas constituée par des philosophes et autres experts académiques », mais bien par les élus à différents niveaux, la société civile et le public en général. Tout à fait d'accord. En général, on peut dire que cette évaluation d'outre-Atlantique (par une personnalité libérale, pas un membre de l'administration Trump) est proche de ce qui vaut pour la Commission nationale suisse.

Une commission nationale doit bénéficier d'une totale indépendance dans ses travaux (et, en principe, quant au choix des sujets qu'elle étudie). Aux USA, elle a en plus la faculté (*action-forcing authority*) d'émettre des recommandations à l'attention d'une agence fédérale, lui enjoignant de prendre certaines mesures - élaborer rapidement des dispositions sur le sujet considéré et les mettre en consultation publique. Toutefois, en pratique, il s'est avéré difficile aux commissions de forcer un département gouvernemental à agir. Capron note encore qu'une fonction des commissions a parfois été d'être une « décharge » (poubelle), s'agissant de thèmes que les responsables doivent avoir l'air de traiter sérieusement mais dont en réalité ils aimeraient se débarrasser...

Conclusion ? « La médecine et la recherche n'ont pas fini de produire des dilemmes éthiques » (un vrai euphémisme) ; aujourd'hui, « le soleil ne se couche jamais sur le monde de la bioéthique ». Et, alors que le Président Trump ne semble pas pressé d'en nommer une, Capron dit l'importance de disposer d'un tel organe, auquel puissent être soumis sans délai les problèmes qui surgissent. La longévité du CCNE français et sa capacité à s'élever au-dessus du politique illustrent à son avis la valeur d'une instance permanente, plutôt que de commissions successives ne durant que le temps d'une législature.

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1. Capron A.M. Building the Next Bioethics Commission. In : Goals and Practice of Public Bioethics : Reflections on National Bioethics Commissions. Special Report, *Hastings Center Report* 47, Supplement to no 3, May-June 2017, pages S4-S9.

## NURSING ETHICS COURSE IN KU LEUVEN. A PERSONAL VIEW

The 6<sup>th</sup> edition of the Intensive Course on Foundational Approaches, Contemporary and Educational Issues in the Field of Nursing Ethics. 6-9 December 2016, Leuven, Belgium

*Tell me... and I'll forget  
Show me... and I may remember  
Involve me ... and I'll understand.*  
Ancient Chinese proverb –  
On the wall of sTimul zorg-ethisch lab

I chose to participate to this course by academic curiosity. My theoretical background is quite close (disability ethics and medical bioethics) and I am dealing with ethical issues presented in cases from the medical practice, reported by physicians and residents. They usually talk about nurses, but not always in a good way and I wanted to know much about their specific challenges, thinking even to propose a course for nurses in my university, or to prepare some lectures on ethics for nurses. So, I wanted to know more about topics, methods and approaches of Nursing Ethics.

The course was an intensive formation that lasted four days. The first day – *Foundational Approaches* – started with an introductory presentation on *Nursing Ethics*, then another one on *Foundational Approaches to Nursing Ethics*, both given by Professor Chris Gastmans (Centre for Biomedical Ethics and Law, KU Leuven), who is also the coordinator of the course. After the presentations there followed a case study and group discussions session, as a practical application of theoretical lectures. The first day ended with a very new, at least for me, and interesting presentation on sexual issues of older people living in nursing homes, given by Lieslot Mahieu (from the same centre, KU Leuven). In the second day – Contemporary Issues – we had a presentation on *Nurses' Responses to Ethical Dilemmas in Nursing Practice*, and group works on the same topic, animated by Professor Bernadette Dierckx de Casterle (Academic Centre for Nursing and Midwifery, KU Leuven). It was also the day of our invited speaker – Professor Helen Kohlen (University of Vallendar, Germany) – who gave us a lecture on *Nurses' end-of-life decision-making in the intensive care unit*, from care policies perspective. The last lecture of the day was on *Palliative sedation: nursing ethics perspectives*, given by Professor Gastmans.

The first half of the third day – Contemporary and Educational Issues – was dedicated to *Nursing ethics perspectives on end-of-life care*, a lecture and a work group session, given and animated by Professor Yvonne Denier (Centre for Biomedical Ethics and Law, KU Leuven). In the afternoon we visit an innovative centre in nursing education, known as sTimul: Care Ethics Lab ([www.uzleuven./stimul](http://www.uzleuven./stimul)). The purpose of this center is to guide and to support institutions of education, care and welfare in sustainable integration of care ethics in practice. After we found out about their mission and about how to do care ethics within organizational context, from Joke Lemiengre, we experienced, by role playing, what means to be old, dependent and, sometimes, alone, but also how the daily work of a nurse with these kinds of patients could be. It was a powerful and unique experience, a very good example for all us (especially those involved in the educational process). In the last day – Methodological and Contemporary Issues – we were introduced the last two topics: *Grounded theory and nursing ethics research: qualitative analysis guide of Leuven*, by Bernadette Dierckx de Casterle and *Nurses and artificial nutrition and hydration decision making at the end of life*, by Chris Gastmans.

All activities done together on Nursing Ethics for four days in Leuven, were a wonderful and inspiring experience: the course contained challenging topics and new methodologies to teach and to conduct studies. I most appreciate the three levels of teaching ethics: as theory, as laboratories (cases) but also as patients or nurses (role play). It helped us to understand the perception on illness, dependency and old ages, but also how to deal with people in such conditions.

**What I learned?** - The meaning and the relevance of Nursing Ethics. New approaches on teaching ethics (focus on three pillars: lived experiences, dialogue between all people involved in ethics and normative standards), key-concepts of nursing ethics: vulnerability, care and dignity. Nursing ethics is at the forefront of topics hotly debated in the last years, like euthanasia and the end-of-life decisions. The ethical essence of nursing care practices is *"providing care in response to the vulnerability of a human being in order to maintain, protect, and promote his/her dignity as much as possible"* (C. Gastmans).

**What I took as a good practice to teach ethics?** - The format of the course. It was done on three levels: theoretical, practical (group work), but also experiential (role play).

**Who were my colleagues?** – Most participants from European countries, but also from some countries in Asia. Most of us are involved in nursing teaching of

practice. All students were interested on topics and activities, providing examples and cases from our countries. Also, the program and activities of students were excellent organized (by Tijs Vandemeulebroucke, MA), and we had a very good time together in Leuven.

**My final conclusion:** It is time to make nursing ethics education, in my country, a priority.

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## 'REIFICATION' AND ASSENT

Report on a Workshop held at the University of Oslo, July 4th 2017

On 4<sup>th</sup> July a workshop was held to discuss "The recognition and reification of non-capacitous human and non-human animals". The workshop was organised by Dr Anna Smajdor of the University of Oslo and attended by an international group of scholars with an interest in discussing ways to give moral recognition to those who lack decision-making capacity in the context of both human and animal research. Addressing both the philosopher Axel Honneth's desire for bioethical engagement with his work, and the increasing interest in the concept of 'assent' in research ethics, discussions sought to apply Honneth's concepts of 'recognition' and 'reification' to the putative need for 'assent' in non-capacitous populations.

The day began with Dr Anna Smajdor (University of Oslo) who gave a paper on Axel Honneth's concept of reification and the ways this concept might be used in

research ethics. Dr Jane Johnson (Macquarie University) followed, discussing the practical, epistemological and ethical status of expressions of dissent by animals used in research. Next, Dr Holly Kantin (University of Alabama) delivered a paper where she considered the normative value of obtaining assent from various types of non-capacitous individuals. Dr Mirja Hartimo (Norwegian University of Life Sciences) gave a paper considering Honneth's concepts of reification and recognition through the lens of Husserl's critique of the 'mathematisation' of science and philosophy. Dr Giles Birchley (University of Bristol) discussed the contrasts and intersections of 'assent' as it appeared in children, people with dementia and animals. Dr Silvia Panizza (University of East Anglia) considered the reification of non-human animals and contrasted this with Iris Murdoch's concept of attention. Finally, Dr Hope Ferdowsian (University of New Mexico) discussed the necessity of respecting bodily sovereignty for health and wellbeing, drawing on empirical evidence of the impact of the denial of bodily sovereignty in animals.

The day ended with a discussion of future directions for our research, and firm plans were made for continued collaboration in this very interesting area.

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## WHY I (WE) WROTE THE ETHICAL JUDGMENTS COLLECTION

[Ethical Judgments: Re-Writing Medical Law](#) (ed. Stephen W Smith, John Coggon, Clark Hobson, Richard Huxtable, Sheelagh McGuinness, José Miola and Mary Neal (Bloomsbury, 2017) paperback and ebook, £40.00 ISBN: 9781849465793

It started with a student. After class one day he asked me about the (in)famous *Airedale NHS Trust v Bland*<sup>6</sup> case. This particular student had been on two of my modules so he knew the case, knew the arguments the judges used and knew what I criticised the judges about. What he didn't know was what I would have done differently. How, he asked, would I have decided the case? After a minute or two of furious thinking, I admitted that I didn't know. This was around the time that the *Feminist Judgments Project*<sup>7</sup> (a fantastic

<sup>6</sup> *Airedale NHS Trust v. Bland*, [1993] AC 789.

<sup>7</sup> R. Hunter, C McGlynn, E. Rackley (eds), *Feminist Judgments: From Theory to Practice* (Oxford: Hart Publishing, 2010).



resource) was published and that led me to think that something similar but focused on ethical decision-making might be a fruitful endeavour. So, I contacted some friends (the rest of the editorial team, including the inquisitive student - by then a PhD student - who started it all) to get together and kick the idea around. As it turns out, some of them had similar ideas. After some good food, some beer, and a lot of discussion, what resulted was the groundwork for what became the Ethical Judgments Project.

Of course, that was merely the basis and most of the hard work needed still to be done. We had decided that we would go with a range of cases which were important in medical law but having also decided to stick to a reasonable number so we could find a publisher, we then had the very difficult task of picking which ones to explore. Well, actually, first we had to decide what constituted a 'medical law' case since some of our potential cases often focused on things other than the relationship between the healthcare profession and the law. *Nicklinson*<sup>8</sup>, for example, talks a lot more about UK constitutional law than it does death and dying. *Axon*<sup>9</sup>, another case we ended up using, focuses more on public law than it does contraception. Luckily, we all liked each other well enough to make it through that morass and come to the rough idea of anything which would reasonably be taught in a medical law course. The seven of us then decided on sufficient cases to constitute a decent range while making sure we kept ones people had been especially keen on (I, for example, insisted *Bland* had to be part of it.) The nine we ended up with [the conjoined twins case (separation of conjoined twins)<sup>10</sup>, *Axon* (contraception for minors), *Bland* (withdrawal of treatment), *Blood* (assisted conception)<sup>11</sup>, *Bolitho* (medical negligence)<sup>12</sup>, *Bourne* (abortion)<sup>13</sup>, *Chester* (causation)<sup>14</sup>, *Nicklinson* (assisted dying), and *St. George's* (treatment of pregnant women)<sup>15</sup>] covered, we thought, the range of medical law about as well as it could be covered while making sure we picked cases we thought our judges could do something interesting with. That's why some of the cases might look a bit strange – why, for example, *Axon* and not *Gillick*<sup>16</sup>, the case which explored the mature minor issue in the first

place? Why *Nicklinson* and not *Pretty*<sup>17</sup> or *Purdy*?<sup>18</sup> In truth, that discussion could have gone on for years and we have no doubt that our ending decisions were controversial. For some of them, though, the answer was that we thought having the line of cases to discuss (rather than the initial starting point) would make for more interesting discussion. That's why we went with *Axon*, *Bolitho* and *Nicklinson* rather than *Gillick*, *Bolam*<sup>19</sup> and *Pretty* (or *Purdy*). In other cases – *Bland* is one – we thought enough of the heavy lifting had been done in the earliest case such that it worked as the focus of discussion. What we ended up with was a mix, but one we thought worked well enough for our purposes. It is not like we conceived of this collection being the one and only attempt ever made on the subject. Even if we had, recent history would have proved us wrong – these kinds of ethical hard cases keep cropping up – *Doogan*<sup>20</sup>, *Montgomery*<sup>21</sup>, *Aintree v. James*<sup>22</sup> and the recent case of *Charlie Gard*<sup>23</sup> provide merely some examples.

Once we had the cases, we then needed contributors and we went with the easiest of options – who did we want to hear talk about these cases and who did we think would do an interesting job. As I hope you agree, the collection of people we ended up with is a fascinating list and all of them took to their task with enthusiasm and vigour. For our judges, we told them that all we wanted from them was to decide the case such that the case would have been legally valid in addition to being ethically consistent – i.e. if they were going to use a set of principles they needed to think through the implications of those principles. They had to decide the case under the law as it existed at the time and all judgments had to stick to a word count of 3,000 words. That last bit was possibly the hardest restriction we put on our judges and many of them (including, by the way, the rest of the editorial team who had all agreed the limit in the first place) cursed my name in new and imaginative ways. We brought most of the contributors together at a workshop halfway through so our judges could then produce their judgments. From there, the judgments went to the commentators who were tasked to respond as either a legal or an ethical commentator (although we accepted a significant amount of overlap). The commentators

<sup>8</sup> R (on the application of Nicklinson and Another) v. Ministry of Justice, [2014] UKSC 38.

<sup>9</sup> Re (on the application of Axon) v. Secretary of State for Health, [2006] EWHC 37 (Admin).

<sup>10</sup> Re A (conjoined twins)(surgical separation), [2000] 4 All ER 961, [2001] Fam 147.

<sup>11</sup> R v. Human Fertilisation and Embryology Authority, ex parte Blood, [1999] Fam 151.

<sup>12</sup> Bolitho v. Hackney Health Authority, [1998] AC 232.

<sup>13</sup> R v. Bourne, [1939] 1 KB 687.

<sup>14</sup> Chester v. Afshar, [2005] 1 AC 134.

<sup>15</sup> St. George's Healthcare NHS Trust v S., [1999] Fam 26.

<sup>16</sup> Gillick v. West Norfolk and Wisbech Health Authority, [1986] 1 AC 112.

<sup>17</sup> R (on the application of Pretty) v. Director of Public Prosecutions, [2001] UKHL 61.

<sup>18</sup> R (on the application of Purdy) v. Director of Public Prosecutions, [2010] 1 AC 345.

<sup>19</sup> Bolam v. Friern Hospital Management Committee, [1957] 2 All ER 118.

<sup>20</sup> Greater Glasgow Health Board v Doogan & Another, [2014] UKSC 68.

<sup>21</sup> Montgomery v Lanarkshire Health Board, [2015] UKSC 11

<sup>22</sup> Aintree University Hospitals NHS Foundation Trust v James, [2013] UKSC 67.

<sup>23</sup> Great Ormond Street Hospital v. Yates, Gard and Gard [2017] EWHC 1909 (Fam).

were less limited than the judges although they too were limited in terms of word count (from which a second round of curses developed). The end result was well worth it (and I barely notice the cloven hooves anymore.)

As a final bit, I want to discuss at least two things we hope people get out of the collection. The first is that judging is hard! Some of the judges (myself included), because we had already thought about these cases for a considerable period of time, decided on an answer pretty quickly. The difficulty is finding a way to articulate the reason for the answer we arrived at. I, for example, stuck with my original view that the doctors ought to have been allowed to remove artificial nutrition and hydration (ANH) from Anthony Bland. I also retained my conviction that the act-omission distinction the judges relied on in the actual case collapses into ethical and legal problems. Intention, though, creates its own issues, not least the fact that the doctors in *Bland*, according to the judges, do want Anthony's life to end as a result of removing ANH. To avoid that thorny problem, you either need to find some way to make motive a part of the criminal law or get creative with concepts of intention. I decided to focus on the latter and, in particular, the difference between an intention to kill and an intention to harm. There were cases which support such a reading although some of them (*R. v. Arthur*<sup>24</sup>, for example) I also dislike. I ended up with a result I could live with although whether it was successful is up for debate (one of the commentators referred to it as 'legal sophistry at its finest' (P. 82)). Others took a different tactic and worked through from a set of first principles and then realised the decision at the end was not what they thought it would be. That led to other concerns as the judges had to decide whether the original principles, the decision, or the reasoning between the two were the problem. All of us, I'd hasten to add, took this seriously. We were not messing around with the duties we felt obligated us in terms of decision-making. Negotiating the serious tensions involved in being a judge, however, meant there was probably a lot more creativity and horse-trading amongst principles than we might have originally thought.

The second thing we would like people to gain from the collection is how embedded these sorts of ethical decisions are in the very fabric of law. As an example, I'd direct readers to the debates in the *Bolitho* and *Nicklinson* judgments which are about considerably more structural questions than they might have initially appeared. This is not to revive or even contribute to the long-running Jurisprudential debate between natural law and positivism. What it is, however, is to stress how frequently decisions in these sorts of hard

<sup>24</sup> R v. Arthur, (1981) 12 BMLR 1.

cases end up relying on deep-seated notions of inherent rightness or wrongness. All of us, whether students, academics, doctors, healthcare workers or judges, cannot help but think ethically when faced with these choices. The very nature of law allows the flexibility for that to happen and while it does not make the cases any easier to solve or less controversial, it probably does make them a little easier for us to live with.

In the end, our biggest hope is that the Ethical Judgments collection is a starting point rather than an ending one. We hope people are inspired by the project to think more carefully about the way that ethics infuses itself into judicial decisions at a whole host of levels. We would like to inspire debate amongst readers in the same way that our judges and commentators discussed these important issues amongst themselves at the workshop and in the collection. That we can start with the same legal system, same legal history and a common set of principles and arrive at such disparate answers is both the fundamental challenge of law in addition to perhaps being one of its biggest strengths.

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## BOOK REVIEW

**“A Guide to Psychosocial and Spiritual Care at the End of Life” by Henry S. Perkins (Springer, 2016) 486 Pages (ISBN: 978-1-4939-6802-2)**

“How long do I have to live, Doctor?” This is the question the patient often asks as a panic-stricken first response to a new fatal diagnosis. I believe that this question is key to this great book written by Dr. HS Perkins, since so much of how the patient responds to his/her diagnosis depends on the doctor's immediate answer.

Dr. Perkins is an internist at the University of Texas Health Science Center in San Antonio and was a bioethics fellow under the guidance of Professor Albert R. Jonsen. After this fellowship, spending time as a missionary in Africa, and working as a clinical ethicist in his hospital, Dr. Perkins came to believe that every illness has multiple important dimensions, not just the bioscientific, and they all deserve attention. The most important dimensions that Dr. Perkins has analyzed are psychosocial, social, ethical, cultural and spiritual. The book is divided into three parts. After the 1<sup>st</sup> chapter, which serves as an introduction, the 2<sup>nd</sup> through the 5<sup>th</sup> chapters present basic information that

the non-medically trained might need to understand the process of medical care; the 6<sup>th</sup> through 14<sup>th</sup> chapters address the psychosocial, social and spiritual dimension of care near the end of life.

The main text of this book is divided into two parts. The first part sketches the basic elements of medical care near the end of life (2<sup>nd</sup>-5<sup>th</sup> chapters). Chapter 2 describes the common end of life symptoms; chapter 3, doctors' methods of diagnostic reasoning; chapter 4 patient benefit/risk assessments of possible treatments; and chapter 5 the problems regarding prognostication, i.e. predicting outcomes when dealing with life-threatening illnesses. The second part of this book addresses specific topics in the nonphysical domains of end of life care (6<sup>th</sup>-14<sup>th</sup> chapters). Chapter 6 discusses advance care planning; chapter 7, proxy decisions; Chapter 8, care of the family in general; chapter 9, care of family caregivers in particular; chapter 10, cultural influences in end of life care; chapter 11, the right to die; chapter 12, going home through death, and the afterlife; chapter 13, bereavement and grief; and chapter 14 spiritual care by HPs. Chapter 15 concludes the book by presenting new directions for end of life research and care.

Dr. Perkins claims that the dichotomy between physical and non-physical aspects in end of life care does not exist. This essential starting point is a concept which accompanies the reader along the course of the entire book. This theme was also recognized and reported as a bioethics issue by Professor Jonsen in his foreword to the book: "Doctors and other Health Professionals have two significant responsibilities, one is to understand the patient as a whole person, to learn about the patient's health-related wishes, and to try to implement those wishes whenever possible; and the other is to ensure faithful, pastor-like care for the patient and his or her closest supporters".

The author starts his reflections about the contemporary need to acknowledge the importance of the non-physical aspects of life and death: the rise of science from the sixteenth century on, however, changed people's attitudes about dying. It became less and less a spiritual event more and more a strictly a physical one. Dr. Perkins however believes that today we should reflect upon, and reassess the importance of non-physical domains for all of the stakeholders in an end of life clinical case. That is why the core focus of this book is daily clinical practice, its difficulties, its dilemmas in relation to the wishes of patients and their nonphysical requests, which medical science seems to be unable to explain in a clear and truthful manner.

Another principal point of Perkins' reflection is the presentation of different methods of making clinical decisions, given that the starting point for addressing such decision-making processes is the certainty of the diagnosis. Dr. Perkins presents four methods – Hypothesis Generation Based on the Diagnostic

Possibilities; Bayesian probabilities; Pathophysiology and Pattern Recognition – their characteristics, potentialities and limitations in the identification process.

In addition, he points out that the doctor often is called upon to illustrate the method he used and to share details regarding critical clinical decision (e.g. to withhold or withdraw treatment and initiate Palliative Sedation) with other persons (patient, family members, medical team). Not only is it difficult to communicate a diagnosis and a possible prognosis, but professionals are also responsible for indicating different care options to that single patient, with his specific wishes and relationships; thus the doctor is often called upon to negotiate about possible end of life conflicting solutions (i.e. in particular in ICUs or in Hospices). Therefore, clinical decision-making processes often seem opaque – especially regarding predictions on survival time – because, as Dr. Perkins writes, none of the concepts is invariable, absolute, or a priori determining. An essential part of the doctor's "art" has always been knowing when to adhere to basic concepts and when to deviate from them – (as Jerome Kassirer, the former editor of the *New England Journal of Medicine* says, medicine is "not a science [but is] based on science"). These aspects are also influenced by the culture in which we are living: today patients are rebelling against "objective, scientific" medical care. They are insisting that health professionals treat them as persons with feelings, relationships and unique life contexts, and not merely as bodies with a disease. In his analysis of these motivations, especially significant during the terminally ill patient's care, the author tries to put together physical and non-physical aspects end of life care. Physical, Psychosocial, Social, and Spiritual domains concern not only the patient but the family members and the proxy as well. These aspects are even more important regarding end of life issues when dealing with individuals from different cultures (i.e. their values and taboos regarding life and death).

As Dr. Perkins reports with well-documented references, relief from physical symptoms is the most important aspect in end of life care, in particular through enhancing physical strength and controlling pain in order to guarantee the highest possible quality of life for as long as possible. Psychosocial health is also a significant aspect of the dying patient's care for both the patient and the family members. Trustworthiness and the interpersonal skills of the health professionals are essential because the patient and their familiars need to believe that the prescribed care will be technically skilled, dependable and compassionate. They also need to believe that the dying patient will be treated respectfully and never abandoned to face death alone. Social factors mean that contacts with family and friends are essential to sustaining patients emotionally through the difficult dying process. Religion and spirituality are also

important aspects in end of life care. Spiritual health, with or without mentioning the idea of a God, is recognized as a significant factor as well.

All of these aspects must be taken into consideration along with two further significant values for the patient: one is the patients' resolving of particular financial, legal and ethical duties at the end of life; the other is avoiding the inappropriate prolongation of dying. In addition to the patient's domains there are those of the family: the first deals with preventing physical and financial burdens on others; the second is preparing the family for death; and the third involves comforting and supporting the family in their grief. Dr. Perkins underlines the importance of considering cultural aspects as well. Every human being is both equal to and different from his peer and every patient-family-doctor relationship involves at least two cultures (one of health professionals and the other of patient). That is why it is important to identify and help to resolve (the acronym of the author's suggested methods is LEARN – it stands for Learn, Explain, Acknowledge, Recommend, Negotiate) cross-cultural issues especially in terminally ill patients' care.

Other more particular aspects of care are described in the book, for example, the possibility of preparing an Advance Care Plan by the patient and the physician. On the one hand patients in general want them, and doctors favor them for many patients who are rapidly deteriorating; on the other hand talking about death is hard because it raises the specter of losing everything, including one's existence.

Dr. Perkins reports different behaviors on the part of patients and doctors regarding the optimal time to discuss Advanced Care Planning. Patients generally want Advance Care Planning discussions earlier in the doctor-patient relationship or earlier in a serious illness than when doctors ordinarily conduct them. The difficulties in Advance Care Planning can be better faced by following some techniques suggested by the author. In general, a good patient-doctor relationship (creating a rapport with patient, asking questions insightfully and listening carefully to patients' answers) can help to break down many of the barriers to Advance Care Planning; in particular thinking positively, fostering trust and using good communication techniques are likely to serve the purpose.

The importance of attention to the nonphysical aspects brings Dr. Perkins to a reflection on the "Right" Way and Time to die. Religion, spirituality, and faith are described in the book as essential aspects of the human experience and much more so when a terminally ill patient approaches death, because it involves a search for meaning and the transcendence of physical life.

Dr. Perkins underlines that during the Twentieth Century westerners experienced the greatest changes ever in death rates. This was brought about by two

factors: firstly, scientific medicine won out over other forms of care by developing reliable cures for many previously fatal diseases; and secondly, patient autonomy took hold, causing patients to demand ever more information and more say about their treatments. These factors also created new confusion over death-related issues: the long-standing belief that God alone determines life or death was suddenly substituted by a new reality in which medical science and patients were also able to make judgements regarding life or death.

Dr. Perkins concludes his book with a piece of advice: we must do better by putting together all of the nuances of human existence in order to better care for each individual human being!

In contrast with the modern mainstream of thought, which sees clinical medicine and the social and spiritual domains of the end of life as differing dramatically, Dr. Perkins disapprove strongly with this compartmentalized approach to end of life. The dying patient's social well-being and spiritual well-being should concern all attending health professionals, especially scientifically trained clinicians. The author offers, in conclusion, some suggestions to Health Professionals who care for dying patients: first, they should ensure the best physical care possible; second, they should cultivate good end of life communication skills; third, they should address the anxieties people have about dying; fourth, they should conscientiously try to understand dying patients' choices about dying and to implement them; fifth, they should emphasize to dying patients and their families the importance of the nonphysical domains of care; sixth, they should do everything possible to eliminate barriers to access, coordination, and continuity of end of life care.

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## BOOK REVIEW

### **Le long cheminement en France de la réflexion sur la fin de vie**

*Recension de :*

Véronique Fournier - **La mort est-elle un droit ?**

Paris : La Documentation Française (Série « Place au débat ») 2016, 164 pages

Le Dr Véronique Fournier a créé le Centre d'éthique de l'hôpital Cochin, à Paris, dont elle a rendu compte de l'expérience dans des publications substantielles

(notamment « Puisqu'il faut bien mourir », 2015), et elle préside depuis 2016 le Centre national des soins palliatifs et de la fin de vie. Dans son dernier ouvrage, elle décrit le cheminement en France, depuis la fin du XXe siècle, des idées et démarches à propos de fin de vie ; dans les milieux de l'éthique, le corps médical, le monde politique, jusqu'à la révision récente, dite Claey's Leonetti, de la loi Leonetti de 2005 sur la fin de vie. Révision qui, quant aux points essentiels, dispose que les directives anticipées du patient s'imposent aux médecins et soignants et ouvre, sous conditions, un droit du patient en fin de vie à bénéficier d'une sédation profonde et continue jusqu'au décès – sédation terminale.

L'auteure reste au plus près de la réalité clinique, rappelant que ces préoccupations se sont aiguisées depuis les années 1970 avec les avancées de la réanimation médicale. Elle considère les questions éthiques et philosophiques de même que le processus politique - tout en prenant du recul par rapport aux combats très marqués d'idéologie du passé récent. Elle souligne comment accorder plus de place au respect de l'opinion de l'autre, et faire un effort concerté de tolérance au meilleur sens du terme, « la voie du dialogue pour le vivre ensemble », serait susceptible d'apaiser une scène politico-sociétale qui a pris des airs de guerres de religion (ce vocable est de J.M.).

En effet, ne devrait-il pas être admissible, et même salué, au pays des droits de l'homme, que des individus majeurs soient en mesure de prendre des décisions concernant leur mort comme ils en prennent à propos de leur vie. Etant entendu que, en aucune manière, la décision de l'un (cas échéant, demander une assistance à mourir) ne saurait être au détriment de la volonté différente de l'autre. Fournier consacre un de ses cinq chapitres à décrire comment cela est mis en oeuvre dans un nombre croissant de pays. « L'une des difficultés du sujet est d'être aux confins de l'individuel et du collectif. Rien de plus respectable que d'avoir sa propre opinion sur la façon dont on aimerait pouvoir mourir. Et pourtant, arrivé à cette extrémité, on a en général besoin d'autrui, donc du collectif, selon la façon dont on conçoit ce que l'on doit à l'autre au nom du vivre ensemble. »

Noter que la question divise aussi la communauté des soins palliatifs : une partie d'entre elle s'oppose inconditionnellement à toute mesure où elle perçoit une « pente glissante » vers l'euthanasie, alors que d'autres voient comment soins palliatifs classiques et, par exemple, la sédation terminale maintenant admise peuvent véritablement être complémentaires, devenant des « soins palliatifs intégraux », et contribuer à une meilleure prise en charge, pour patients et proches.

Fournier relève que la résistance est jusqu'ici souvent plus forte dans les milieux soignants, pour des motifs qu'on peut comprendre - la crainte d'être de plus en plus souvent témoins de fins de vie « décidées » (« commercer quotidiennement avec la mort »). Aussi, les empoignades philosophiques n'ont rien fait pour une compréhension plus posée des réalités pratiques. « On ne peut pas laisser des situations pourrir au nom du dogme de la mort naturelle », il importe de « travailler loin de tout dogmatisme ». Ceci alors que les études d'opinions montrent qu'une majorité de Français se disent ouverts à un droit de décider de sa propre mort.

Difficile de savoir comment les choses vont évoluer. Il n'est pas exclu que 149 « le socle de la loi Claey's Leonetti soit trop instable, puisque fondé sur la ligne de crête d'un improbable compromis, susceptible de ne contenter ni les partisans de l'ouverture d'un droit à mourir ni ses opposants. » Devant l'histoire récente de désaccords, l'auteure n'ose guère espérer pour bientôt l'avènement d'un véritable consensus. Regrettable - mais le pire n'est jamais certain.

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## ANNOUCEMENT

### 2017 EACME Annual Conference

September 7-9, 2017, Barcelona, Spain

#### “Justice in Health Care – Values in Conflict”

The oldest bioethics centre in Europe, the Borja Institute of Bioethics-Ramon Llull University, and the European Association of Centres of Medical Ethics (EACME) is hosting the 2017 EACME Annual Conference.

The Borja Institute of Bioethics-Ramon Llull University (Barcelona) was founded in 1976 with the main goal of studying in depth the problems raised by progress in biomedical science and its implications for society and its values, disseminating its findings in specialized publications. Recent developments in various countries in Europe, like for example austerity measures, lead to concerns about the conflict between justice in health care with various other, economic and political, values. That is why we wish to discuss the following topics with you:

- Determinants of Health

- What does health mean? Looking beyond WHO definition
  - Lifestyles and health
  - Quality of life
  - Social expectations and medicalisation of life
  - *Salutogenesis* and health-promotion activities
- Healthcare Systems: at the Service of What?
- Ethical issues in different models of Healthcare Systems
  - Sustainability
  - The role of Primary Care in health systems
  - Ethics issues in research with *big data*
  - Designing future healthcare systems
- Justice and Vulnerability
- Social inequalities in health
  - Mental health care
  - Care for people with disability
  - Childcare, Elderly care
  - End-of-life care
- The Role of Professionals and Research
- Professionalism and decision-making
  - Effects of austerity measures on health care
  - Quaternary prevention
  - The clinician as a manager of resources
  - Continued education
  - Responsibility and integrity in research

We are waiting for you in Barcelona!

Institut Borja de Bioètica, Santa Rosa, 6. 08950  
Esplugues (Barcelona, Spain) [www.ibb.url.edu](http://www.ibb.url.edu)

<http://eacme2017bcn.org/>

## NEW BOOKS

**David Albert Jones, Chris Gastmans, Calum McCalum (Eds.) Euthanasia and Assisted Suicide: Lessons from Belgium. Cambridge: Cambridge University Press. 2017 (ISBN: 9781 107 198869)**

Examining the evidence from Belgium – one of only five countries where euthanasia is practiced legally – an international panel of experts considers the implications of legalised euthanasia and assisted suicide. Looking at the issue from an international perspective, the authors have written an in-depth analysis of the ethical aspects of this complex area, appealing to law, philosophy and medical disciplines. The discussion forms a foundation for informed debate about assisted dying and provides a useful guide to similar choices faced by other jurisdictions.

Chris Gastmans

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**Mark Schweda, Larissa Pfaller, Kai Brauer, Frank Adloff, and Silke Schicktanz (eds.), Planning Later Life Bioethics and Public Health in Ageing Societies, Abingdon: Routledge 2017**

I am pleased to announce the publication of the edited volume “Planning Later Life Bioethics and Public Health in Ageing Societies”. The book examines the relevance of modern medicine and healthcare in shaping the lives of elderly persons and the practices and institutions of ageing societies. It is therefore of high interest to EACME’s focus on moral values and ethical theory in the context of healthcare practice, biomedical research and healthcare systems. Combining individual and social dimensions, “Planning Later Life” discusses the ethical, social, and political consequences of increasing life expectancies and demographic change in the context of biomedicine and public health. It includes contributions by Kai Brauer, Paul Higgs and Chris Gilleard, François Höpflinger, Søren Holm, Nancy Jecker, Ralf J. Jox, Stephen Katz and Peter J. Whitehouse, Andreas Kruse, S. Jay Olshansky, Larissa Pfaller and Frank Adloff, Thomas Rentsch, Silke Schicktanz, Mark Schweda, Ruud ter Meulen, Perla Werner, and Hsiu-I Yang. By focusing on the field of biomedicine and healthcare, the authors engage readers in a dialogue on the ethical and social implications of recent trends in dementia research and care, advance healthcare planning, or the rise of anti-ageing medicine and prevention. Bringing together the largely separated debates of individualist bioethics on the one hand, and public health ethics on the other, the volume deliberately considers the entanglements of envisioning, evaluating, and controlling individual and societal futures. So far, the process of devising and exploring the various positive and negative visions and strategies related to later life has rarely been reflected systematically from a philosophical, sociological, and ethical point of view. As such, this book will be crucial to those working and studying in the life sciences, the humanities, and the social sciences, particularly in the areas of bioethics, social work, gerontology and aging studies, healthcare and social service, sociology, social policy, and geography and population studies.

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