

# EACME Newsletter

European Association of Centres of Medical Ethics

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## EDITORIAL

Dear Friends and Colleagues,

I am pleased to present you with the new EACME-Newsletter. In this edition you will receive insights into a variety of subjects, such as a PHD-Project of the Swansea University, clinical research with children in Spain and the birthday of the Centre of Ethics Medicine in Bristol, UK.

Additionally, I am happy to announce that we found a new title for our honorable EACME price. Annually, the EACME price is awarded to PHD-Students who submit a conference abstract that distinguishes itself in clarity, coherence, innovation and ethical reflection. The new name of the price is: Paul Schotmans Price. This title was chosen in honor of Emeritus Professor and previous EACME President Paul Schotsmans from Leuven, Belgium.

And with the word "Leuven" we already find ourselves at the annual EACME Conference. This conference will be held between September 8<sup>th</sup> and September 10<sup>th</sup>, in Leuven. This year's conference promises to become the biggest one in the history of EACME. As you will be able to read in the paragraph below, 200 participants have applied with their abstracts. Please come along as well. We would be delighted to welcome you.

On this note, and as we are already talking about conferences: you might want to circle September 7<sup>th</sup> until 9<sup>th</sup>, 2017 in your calendar as well. This is the date when the next EACME conference will take place in Barcelona. It will be organized by the Borja de Bioethica Institute of the University Ramon Llull.

I wish you a pleasant read,

Rouven Porz, Editor

## 30 YEARS OF EUROPEAN BIOETHICS

In 2016, both the European Association of Centres of Medical Ethics (EACME) and the Centre for Biomedical Ethics and Law of the Catholic University of Leuven (Belgium) celebrate their 30<sup>th</sup> anniversary. An excellent occasion for the annual EACME Conference to reflect on the past, present and future challenges of European Bioethics. Where do we come from? What are the present issues at stake? And what will the future bring?

The focus of this year's conference is on a variety of highly relevant ethical issues in health care:

- Organizational Ethics in Health Care: Principles, Cases and Practical Solutions
- Ethical Issues in Care for Older Persons
- Ethical, Legal and Social Developments in Human Genomics
- Ethics and Integrity in Research

More than 200 abstracts on the above mentioned topics were submitted by researchers who want to share their insights with colleagues from all over the world. The historic town center of Leuven hosting the oldest university of the Low Countries provides excellent opportunities to meet each other academically as well as in social activities.

The conference committee

## EACME PROFESSOR PAUL SCHOTSMANS PRIZE WINNERS 2016

It is our pleasure to announce our EACME Professor Paul Schotsmans prize winners for the annual conference 2016 in Leuven.

**Anna Genske** (Ceres, Cologne Center for Ethics, Rights, Economics, and Social Sciences of Health) will be awarded with the "Paul Schotsmans prize" of 500 Euros to her scientific contribution "Prescription of Drugs: Yes, Dialysis: Maybe, Heart Surgery: No? Decision-Making Capacity and the Notion of Relativity in Dementia Patients - A Comparative Analysis in Medical Ethics and Law".

**Marcello Ienca** (Institute for Biomedical Ethics Basel) will receive a "second" prize, as both abstracts were quite close in our Daily Board selection, for his scientific contribution "Proactive Ethics for Empowering Technology: Critical Issues in Technological Innovation for Dementia Care".

Congratulations winning these EACME Professor Paul Schotsmans prizes!

Emeritus Professor and Past EACME President Paul Schotsmans will present these EACME Professor Paul Schotsmans prizes together with our President Professor Ruud ter Meulen during the Leuven conference on Thursday, 8 September 2016 at 16.45 hrs: Promotion Room in the University Hall

We hope to see you all in Leuven!

For more information about the conference:  
<http://www.eacme2016.org/>

Daily Board EACME

## TWENTY YEARS OF BRISTOL'S CENTRE FOR ETHICS IN MEDICINE

2016 is the 20<sup>th</sup> anniversary of Bristol's Centre for Ethics in Medicine. Based in the School of Social and Community Medicine in the Faculty of Health Sciences at the University of Bristol, England, the Centre has gained an international reputation for its endeavours in research, education, and engagement.

### The First 20 Years

Thanks particularly to the efforts of Professor Gordon M Stirrat, the Centre was established in 1996 with the appointment – to the first Chair in Ethics in Medicine at a UK Medical School – of Professor Alastair V Campbell. Professor Campbell directed the Centre until 2006, when he was succeeded by Professor Ruud ter Meulen, the President of EACME. Following Professor ter Meulen's retirement in 2015, Professor Richard Huxtable assumed the role of director.

A great deal has been achieved in the first twenty years of the Centre. There has been pioneering research – funded by grants from, amongst others, the Wellcome Trust and the European Commission – on a range of topics, including end-of-life care, human enhancement, human tissue, clinical ethics support, non-invasive prenatal testing, and methodology in bioethics. The Centre has hosted leading bioethics conferences, such as the World Congress of the International Association of Bioethics and, of course, the 25th anniversary conference of EACME in 2012 (see *EACME Newsletter* 2012; 32 (Dec): 2-3), which culminated in the volume *The Voices and Rooms of European Bioethics* (Routledge, 2015). There has also been a host of engagement activities, from appearances in the international media, to work with science centres, museums and theatre companies. In both our engagement and research activities, we have been fortunate to involve many of our students, from undergraduates to postgraduates, who have been

studying with us for the MBChB in Medicine, the intercalated BSc (Hons) in Medicine, Masters' qualifications and of course PhDs.

### Celebrating 20 Years

To mark this milestone, 2016 brings a variety of events, outputs and initiatives, about which we'll be tweeting (#CEM20). Amongst the outputs are research papers, such as those from Dr Zuzana Deans, on conscience, and Dr Giles Birchley, on harm, in a recent edition of the *Journal of Medical Ethics* (2016; 43(2) (Feb)). Professor Richard Huxtable is part of the team behind the forthcoming *Ethical Judgments: Re-writing Medical Law* (Hart, 2016), whilst Dr Jonathan Ives, who recently joined us as Senior Lecturer in Biomedical Ethics and Law, has co-edited the forthcoming *Empirical Bioethics: Practical and Theoretical Perspectives* (Cambridge University Press, 2016).

Various research projects are also under way. Professor Huxtable and Dr Birchley are undertaking work on the "best interests" standard in medical ethics and law, as well as exploring the ethical dimensions of "smart" houses. Dr Deans, in collaboration with (now Emeritus) Professor ter Meulen, is leading work on research integrity. Dr Ives continues to lead projects on methodology in empirical bioethics research, whilst also exploring the ethics of parenting. Plans are also in place to further develop work around dying well with reduced agency, surgical innovation, clinical ethics support, assent, discretion and even sex robots. We hope to make research appointments in relation to some of these projects, so would invite those who are interested in working with us to await adverts in due course.

The 20<sup>th</sup> anniversary is also being marked by a range of events, conferences and workshops. There has been a successful conference, co-organised with a local Law firm, on "Capacity and End of Life Care", plus workshops associated with the "best interests" project and also with collaborators from Kyoto University. Professor Huxtable has additionally been involved in ground-breaking exhibitions at Bristol Museum, on "Death: The Human Experience" and "Death: Is it your Right to Choose?", the latter of which involved assisting in the recreation of a Dignitas room and chairing a public debate on assisted dying (a recording of which is available via the Museum's website). Dr Deans has also helped our BSc (Hons) Bioethics students to host their ever-popular annual conference, which this year explores "Gender, Relationships and Equality".

Of particular note is our proposal to host the 10<sup>th</sup> annual meeting of the UK Postgraduate Bioethics

Conference, which will run in September 2016. The coincidence of the two anniversaries makes Bristol the ideal location, not least as the inaugural conference was co-organised by Dr Ives (before he was Dr!). The conference is, distinctively, co-ordinated by postgraduate students, working in collaboration with the Centre team, including our honorary fellows. This year's theme is "Bioethics in Theory; Bioethics in Practice". The organisers, led by Louise Austin and Georgina Morley, are applying for funding, in the hope we can keep costs low for postgraduate students who wish to attend to present their work. There will be a range of keynote speeches, interactive panels, and career development sessions, with the emphasis on enabling postgraduates to discuss their work and meet others in the field. A call for papers will be publicised by EACME and, although spaces are limited, we hope to welcome as many of you as possible to Bristol this September, so we can continue to celebrate #CEM20 together.

Richard Huxtable

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### CHILDREN AND CLINICAL RESEARCH: JOINING EFFORTS

Clinical research with children raises a number of ethical questions, and is one of the unresolved issues in bioethics at the international level. The Víctor Grifols i Lucas Foundation have addressed the issue of clinical research before, but we had never focused on the question of research involving children and adolescents. The Foundation already had a partnership agreement with the Nuffield Council on Bioethics, and when we knew that Nuffield was preparing a report on this topic we proposed that we contribute to the project.

After several exchanges between the two institutions, the idea of organizing a seminar in Barcelona was mooted, with the aim of giving British and Spanish researchers a chance to compare points of view and to share experiences. The meeting also provided an opportunity to present the Nuffield's report Children and clinical research, which had just been published. The document analyzes how to conduct clinical trials with children and young people in a manner that is ethically acceptable, ensuring that they are fully involved. It addresses issues such as the roles of the

different parties involved, the protection and participation of minors on the basis of their maturity, and the defining conditions of such studies. As part of its commitment to sharing the information contained in the report with a wider audience, the Víctor Grífols i Lucas Foundation sponsored two editions of the document in Spanish: an informal and very visual edition, aimed at children and families, and a more specialist version, for health professionals.

As part of the event, jointly organized by the two institutions, Nuffield also presented an animated short film for children. The film is told from the perspective of a child who goes through some of the questions and issues that might be raised when a young person is invited to take part in clinical research. After the screening, the Víctor Grífols i Lucas Foundation decided to help it find a wider audience, working with Nuffield and design providers to translate and edit it into Spanish. To date, it has been viewed over 4,500 times.

Finally, the Foundation has just published the report "Ethical aspects of research with children", which brings together the papers presented at the seminar in Barcelona. This brings to a close our cooperation in this area, but we remain committed to working with the Nuffield Council on other topics. Until next time!

All the documents, videos and publications can be accessed via the website of the Foundation at [www.fundaciogrifols.org](http://www.fundaciogrifols.org) and of the Nuffield Council at [www.nuffieldbioethics.org/children](http://www.nuffieldbioethics.org/children)

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## PHD STUDY SUMMARY

### Care Continuity and Quality of Life for People at the Interface of Primary and Secondary Mental Health Care in Wales

The aim of this PhD research study is to examine care continuity experiences and quality of life for people with serious mental illness (SMI) in Wales who have recently had their treatment transferred from secondary to primary care. This group of people may be considered to be at the interface of primary and secondary mental health care in Wales. Traditionally, secondary care has been the predominant means for provision of mental health care for people with SMI in the United Kingdom. More recently however, there has been a shift towards primary care as an appropriate

context for the treatment of people with SMI (Lester et al., 2004; WHO, 2008).

Within mental health services in the UK, secondary care usually involves a community mental health team, with the option of hospitalised inpatient care. Mental health care at the primary level may be delivered by various practitioners working through a GP practice, providing services such as comprehensive mental health assessments, medication and short-term therapeutic treatments like brief CBT. The Mental Health (Wales) Measure 2010 is a piece of legislation which features strongly in a move towards primary care delivery for people with SMI in Wales. Part 2 of the Mental Health (Wales) Measure 2010 has led to a number of people, who were previously treated within secondary care, to be discharged into primary care. This is because Part 2 of the Measure requires all people with SMI who are treated in secondary services to have a Care and Treatment Plan (CTP) and a care-coordinator. These two new requirements have led to the following process whereby a significant group of people with SMI have been discharged from secondary to primary care.

A number of people with SMI being treated within secondary care have traditionally been held on psychiatrists' outpatient lists and did not have a CTP or care coordinator. However, psychiatrists did not have the working capacity to become care coordinators or provide a CTP for this group of people, once the requirements of Part 2 of the Welsh Measure came into effect. Consequently, they attempted to refer these individuals to community mental health teams. Community mental health teams did not have the capacity to take on all these new patients, so the solution was to discharge many of them into primary care. Emerging evidence is illustrative of this process, which is considered to be an unforeseen consequence of the Mental Health (Wales) Measure 2010 (Gofal, 2015; ORS, 2014; Welsh Government, 2014).

There is concern about whether the primary level is an appropriate care pathway for people with SMI. A recent survey in Wales showed that 72.2% of primary care staff described the area of mental health care as 'difficult' or 'very difficult' to manage (WaMH in PC, 2015). Another recent study in south London has shown that 58.2% of people discharged from secondary to primary care were referred back to secondary care within two years of their original discharge (Ramanuj et al., 2015). Of these individuals, 60.3% were experiencing a crisis in their mental health condition at the time of referral. The high proportion of people being referred back to secondary care within two years, many of whom were at a point of crisis, suggests that there may be inadequacies in mental health care at the primary level. Ideally treatment

should be delivered as an early intervention prior to the person reaching the point of crisis, since this can often improve prognosis and may prevent future need for specialty care. The study by Ramanuj et al. (2015) would seem to indicate that early intervention strategies are not being implemented adequately at the primary level. In addition to problems with service delivery within primary care, there are indications that shortfalls may also be due to interruptions in care continuity at the point of transition or interface between secondary and primary levels.

The requirement that all patients in secondary services must have a CTP and care coordinator would appear to represent an improvement in healthcare service standards. However, the unforeseen interaction between the implementation of this new standard and high caseloads among community mental health teams has seen the result that significant numbers are discharged to primary care. If it is the case that there are shortfalls in primary healthcare delivery for people with SMI, the intention to improve service standards inherent in Part 2 of the Welsh Measure may actually lead to a degradation of service quality rather than an improvement in care standards.

The concept of 'wicked problems' may shed some light on the contradictory nature of this dynamic process. 'Wicked problems' occur within complex systems where apparent solutions in one context generate waves of consequences and undesirable repercussions in another area (Hannigan & Coffey, 2011). These undesirable repercussions may be detrimental to the point of outweighing the original intended benefit. Healthcare service structures may be regarded as examples of complex systems (Plsek & Greenhalgh, 2001). Mental health services in the UK could be seen as a particularly complex part of the NHS because of the way in which services have been developed over time in a piecemeal and fragmented manner, often without systematic planning. Frequent policy changes have led to repeated service transformations which have triggered profound and unexpected ramifications. For example, the construction of large psychiatric hospitals in the past led to the protracted difficulties of institutionalisation and stigmatisation. The concept of 'wicked problems' provides a framework within which it may be understood how unpredictable and detrimental results are produced by policies intended to do good, in a complex and interconnected mental healthcare system.

In this vein, the impact of Part 2 of the Mental Health (Wales) Measure 2010 may be seen as the latest example in a long line of policy outcomes which are 'wicked' in their nature. 'Wicked' in this sense does not mean ethically deplorable but it does signify a complex

chain of events which may be considered to be undesirable or even malignant in nature. In this new case of mental health service reform, a policy intended to lead to increased rigour in service standards may have led to a detrimental effect on services, if shortfalls in primary mental health care delivery are present. This situation can be considered to entail a significant ethical dilemma given that medicine and mental health care are fundamentally moral undertakings (Barker, 2011). The care and treatment of vulnerable persons such as people with SMI is an important moral concern for any civilised society (Ahmedani, 2011). The potential creation of a 'wicked problem' as a result of a measure intended to improve service quality may be considered to be an ethical problem in a very real sense, if this is to have a detrimental effect on our ability to care for the more vulnerable members of our society.

The contemporary context of prudent healthcare for the Wales NHS may be related to the idea of 'wicked problems', since both may be understood in an ethical context. Prudent healthcare may be considered to be governed by the ethical normative of austerity, whereas 'wicked problems' may have a profoundly ethical significance if they entail a reversal of good intentions. Prudent healthcare principles advocate goals such as a patient-centred system, equity based care, co-production and increased efficiency through more effective use of skills and resources (Bevan Commission, 2013). It might be argued that increased efficiency is achieved through a greater emphasis on primary care delivery for SMI, since primary care is considered to be more cost-effective than secondary care (Dijk et al., 2014). However, if this leads to a 'wicked problem', the virtuous intent of prudent healthcare can be considered to have backfired, and the 'wicked' result of lower standards of care for vulnerable people will have occurred instead. Accordingly, one of the central concerns of this PhD research study will be to determine whether prudent healthcare objectives have been achieved, or whether this agenda has been confounded by a 'wicked problem'. The PhD study will therefore conduct an in-depth examination of care continuity experiences and quality of life for people with SMI who have had their treatment transferred to primary care in Wales.

Finally, it is important that the right ethical balance is struck when it comes to carrying out research with vulnerable populations, such as people with SMI. Whilst important precautions should be taken when conducting research with vulnerable adults, these precautions should not be so great that they are excluded from research altogether. Such exclusion would prevent many researchers from making progress in the understanding of the care and treatment of those with mental disorder, and deny

historically disempowered groups a right to contribute to important research (Hewitt, 2007). A central point here is that an assumption of global irrationality should not be made on behalf of individuals simply by virtue of their having a mental illness (Hewitt, 2010). The view that unintelligibility is the central characteristic of mental ill health inevitably leads to the exclusion of people with SMI from important discourses such as research enquiry, and an entrenchment of their disempowered state. In view of the potential 'wicked problem' which has resulted from a service transformation implemented in the spirit of prudent healthcare, it is important that vulnerable adults whose care has been negatively impacted by this change are given a 'voice' with which to express their plight. One of the principal motivations behind this PhD study is a desire to facilitate this process.

Nick Weaver and Jeanette Hewitt.

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## WELCOME TO OUR NEW EDITORIAL MEMBER: MARIA ALUAS

### PERSONAL STATEMENT – MARIA ALUAS –

I have obtained my bachelor's degrees in Theology and French Language and Literature in 1998, and in Law, in 2007 within Babes-Bolyai University in Cluj-Napoca, Romania. I started to become interested in Bioethics since I was a student in Theology, due to my interests, especially in Moral Theology. After I graduated Law School, in 2007, I started to work at the Center for Bioethics of Babes-Bolyai University, the first center and the only one, on Bioethics in Romania.

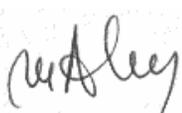
At the beginning of my activity in Bioethics, I did several translations of papers and official European documents in order to provide language-based materials for my students with the aim of a better understanding of Bioethics issues. In 2009, I started to study Bioethics in a more systematic way, in Italy, as a postdoctoral researcher within an EU financed project, MURINET, focused on Research Network on Health and Disability in Europe within the Center for Bioethics of Catholic University in Milan, in a team headed by Professor Adriano Pessina. It was a great opportunity for me to study and understand these very complex fields of research, which are at the intersection of many disciplines, such as: medicine, law, ethics, psychology, sociology, and statistics. My main focus was in how to understand disability condition and how to appropriate this field of research to bioethics. I also tried to set up some characteristics of the Romanian context in understanding and defining the disability and people with disabilities. In 2011, I moved back to Romania and, in 2012 I started to work as senior lecturer at Iuliu Hatieganu University of Medicine and Pharmacy, in Cluj-Napoca, Romania. Being involved in

activities with students and residents, I figured out the necessity for Romanian young physicians to understand deeply and in a proper way the complexity of their practices and the importance of bioethics for their profession. For this reason, I worked on my book, where I treated the main topics of contemporary bioethics and I tried to clarify concepts, definitions, and paradigms in this field. Even though we are at a basic level of wide spreading this topic, they are paying attention and show interest, and mainly they understand the role of Bioethics in their future profession. Because of these, I strongly believe that they have a huge potential to do great things and develop their profession in a right and complete way. As examples, I could mention our activities within Bioethics laboratory, several invitations with oral presentations to different congresses, workshops and conferences organized by students of Medical School in Cluj. From the beginning of 2016, I am working also as a legal advisor for the College of Physicians from Alba-Iulia County. Thus, I am working on concrete problems and issues of physicians and patients in the day-by-day medical practice. As a faculty member and course coordinator on Bioethics, my research interests focus primarily on the intersection between biomedicine, ethics and law issues. Current projects focus on bioethical issues associated with medical ethics and deontology, establishing Bioethics committees, and the influence of religious in the field of bioethics debate. Another direction of my research preoccupation is the issues regarding clinical ethics and clinical ethics committees. Topics as advance directives, conscientious objection, end-of-life decisions and the right to refuse treatments, or the procedure to inform patients about medical interventions and how to understand and assume risks and consequences are not very used in medical and legal practice in Romania.

Taking into consideration all the aspects above mentioned, this is the reason why I focus on these topics and why I am trying to understand the fundamentals of medical and legal practices in Romania.

Cluj-Napoca  
Assist. Prof. Maria Aluas Ph.D

30 -03- 2016



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## IN MEMORIAM: JEAN-FRANÇOIS MALHERBE (1950 – 2015)



A few days before Christmas I received the - for me at least - shocking news that Jean-François Malherbe had passed away. Born in Brussels (1950), he was a doctor in philosophy (Louvain, 1975) and theology (Paris, 1983). He was professor of medical ethics at the Faculty of Medicine of the Université Catholique de Louvain (UCL) (Belgium), at the Université de Sherbrooke in Québec (Canada), and later on professor of moral philosophy at the University of Trento (Italy). Besides bioethics and moral philosophy, he was interested in Eckhart (see his book *Maître Eckhart. Souffrir Dieu*, Paris, Cerf, 2003).

There are many reasons why this news touched me personally and I will explain them later in this obituary. I limit my "in memoriam" to his role in my personal career, in EACME and the Belgian bioethics scene.

When the Leuven Centre for Biomedical Ethics and Law was created in 1986, we had an important forerunner in Belgium, namely the "Centre d'Etudes Bioéthiques" at the French speaking Catholic University of Leuven, Louvain-la-Neuve. Close by the stage Alma (metro in Brussels) (you had simply to go out and you were at the entrance of the Centre), an impressive space was made free to host the Centre d'Etudes Bioéthiques. Jean-François was the director, Edouard Boné s.J. his main collaborator, and many others were active in this Centre, like our colleagues Pierre-François Cobbaud and Pierre Boitte. The Centre organized intensive courses, conferences and congresses in these lightning early days for bioethics in Europe. It was probably – at the beginning – one of the best financed and sponsored Centres of our continent.

Jean-François was my companion from the start of my bioethics-career. He stimulated me – as newly appointed professor in medical ethics – to go abroad

(e.g. Georgetown University) and to observe how other Centres of Bioethics work and function. At a certain moment, he challenged me to use my university resources (and they were – and still are - limited) for a visit to Barcelona...indeed, Francesc Abel in Sant Cugat, nearby Barcelona, had also created a beautiful Centre, probably the first bioethics Centre on the European continent.

I will never forget this trip (1985): the story is at the same time illustrative for the personality of Jean-François. Of course, we had to work: we had a full day visit of Francesc's Centre...it was by the way my first meeting with Francesc (we worked later intensively together in the context of EACME and the Fédération Internationale des Universités Catholiques). We were received with great hospitality and instructed how to create and manage a Centre of Bioethics. After this one day intensive work, Jean-François planned other activities: excellent dinners in Barcelona city, a visit to Gaudi's Cathedral, a visit to several splendid museums in Barcelona and also to the monastery of Montserrat outside the city. It was wonderful...Jean-François was a most inspiring guide, meanwhile instructing me about his ideas concerning bioethics. So, working and enjoying life went splendidly together.

In the eighties, we celebrated our birthdays (same year of birth, even in the same week) regularly together. We published common public opinion statements. We co-organized the first Bioethics Conference in Belgium, both open for a fully pluralist participation, also in the organization. The Belgian Secretary of State of that period, Wivina De Meester-Demeyer, sponsored our collaboration and made it possible that the first Belgian Bioethics Conference (1987) was an enormous success, with great participation from all universities in Belgium: bioethics was now also on the Belgian map.

For EACME, Jean-François – always with the help of Edouard Boné – may be considered as one of the founding fathers. He was from the beginning Secretary-General and he brought creativity in our activities. He was so well known and respected that he travelled all over Europe, a fully multilingual and creative personality as he was.

Personal evolutions in his life made that he had to leave Belgium to continue his activities in Canada and Italy. We lost contact and could not find an opportunity to restore our relationship. But, again – after recently Maurice de Wachter, after Francesc Abel – one of the most inspiring figures of EACME has passed away. I – and all the members of EACME – present our condolences to all those who loved him.

Paul Schotsmans

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Définitivement dans nos coeurs

Le nomade polyglotte



Jean-François Malherbe  
1950-2015

## BOOK ANNOUNCEMENT

### Henk ten Have: Vulnerability: Challenging Bioethics

Routledge: London and New York, 2016, 252 pages  
ISBN 978-1-138-25267-5

Alongside globalization, the sense of vulnerability among people and populations has increased. We feel vulnerable to disease as new infections spread rapidly across the globe, while disasters and climate change make health increasingly precarious. Moreover, clinical trials of new drugs often exploit vulnerable populations in developing countries that otherwise have no access to healthcare and new genetic technologies make people with disabilities vulnerable to discrimination. Therefore the concept of 'vulnerability' has contributed new ideas to the debates about the ethical dimensions of medicine and healthcare.

This book explains and elaborates the new concept of vulnerability in today's bioethics. Firstly, Henk ten Have argues that vulnerability cannot be fully understood within the framework of individual autonomy that dominates mainstream bioethics today: it is often not the individual person who is vulnerable, rather that his or her vulnerability is created through the social and economic conditions in which he or she lives. Contending that the language of vulnerability offers perspectives beyond the traditional autonomy model, this book offers a new approach which will enable bioethics to evolve into a global enterprise.

This groundbreaking book critically analyses the concept of vulnerability as a global phenomenon. It will appeal to scholars and students of ethics, bioethics, globalization, healthcare, medical science, medical research, culture, law, and politics.

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## BOOK REVIEWS

**Véronique Fournier**

**Puisqu'il faut bien mourir - Histoires de vie, histoires de mort: itinéraire d'une réflexion**  
**Paris : La Découverte, 2015, 248 pages.**

« La médecine aujourd'hui est allée si loin (...) La contrepartie, c'est que la mort ne vient plus toute seule. Dans bien des cas il faut désormais décider qu'elle survienne, faire quelque chose. On est souvent conduit à agir la mort. » Véronique Fournier, cardiologue et médecin de santé publique, a fait partie du cabinet de Bernard Kouchner, en lien avec la loi de 2002 sur les droits des malades. La même année, elle crée le Centre d'éthique clinique de l'hôpital Cochin, s'engageant avec une considération du vécu des patients et/ou de leurs proches qui impressionne. Ce dernier ouvrage traite de la fin de la fin de vie, encadrée depuis 2005 par la loi Leonetti et qui reste un sujet d'actualité sociétale et politique. Dix chapitres, l'essentiel du livre, présentent une succession de situations pour lesquelles son Centre a été consulté par des proches de patients, des malades eux-mêmes ou des équipes soignantes ; à propos de personnes soit en état neurovégétatif chronique, soit en fin de vie d'une maladie de type Alzheimer ou neurologique.

L'auteur adopte une position ouverte qui diffère de celles où les opinions émises sont contraintes par un ou plusieurs principes dits d'emblée non-négociables et où, en excluant certaines options, on réduit significativement l'angle de vision et de réflexion. « Nous ne concevons pas notre activité comme ayant pour vocation de dire le bien et le mal, non plus que dire l'éthique à vrai dire. C'est la méthode dont il nous importe qu'elle soit éthique. En fait nous concevons plutôt notre pratique comme un exercice de solidarité citoyenne, due à ceux qui en ont besoin (...) 'Vérité en deçà des Pyrénées, erreur au-delà' disait Pascal. Peut-être faut-il savoir accepter avec lui que même la vérité est un concept à géométrie variable. » Il ne saurait y avoir une seule attitude correcte : « Là encore, c'est la confrontation avec les non-médecins qui m'a fait avancer (...) Les non-médecins s'y retrouvent mieux avec la logique apportée par la loi Leonetti. [Admettant] l'idée que tout traitement même mineur peut être jugé excessif. Au fond il s'agissait désormais d'admettre que l'obstination déraisonnable était devenue une notion subjective: à chacun son seuil de tolérance. »

La réflexion interdisciplinaire est une composante essentielle de la démarche du Centre de Cochin : importance de « la confrontation à la pensée de l'autre. De celui qui est d'une autre discipline, qui n'a pas été élevé à penser pareil, qui est étranger. En acceptant

de se confronter à la réalité concrète de la vie telle qu'elle est, et non telle qu'elle est manipulée dans les débats d'idées. La pensée s'est construite à plusieurs, venus d'horizons différents.» L'expérience de l'équipe l'a convaincue que, quand des proches qui se sont dévoués durant des années pour un malade demandent que quelque chose soit fait pour mettre un terme à son existence, il importe d'en tenir compte. « Il n'y a que ceux qui s'approchent au plus près de ces patients qui peuvent dire s'il y a obstination déraisonnable (...) Leur demande est juste, ils n'ont aucun doute là-dessus et supportent mal les théories psychologisantes et incantations moralisantes. Qui sont-ils pour me faire la leçon ? »

Et Fournier : « Le plus honorable que nous puissions faire collectivement pour eux, c'est de leur faire confiance, à eux plutôt qu'à nos machines sophistiquées. » Pour l'auteur, la position d'accompagnement comme posture éthique (plutôt que celle de recommandation voire prescription morale) est un choix de plus en plus répandu parmi les équipes médicales. Cas écheant, le fait de permettre à une existence de se terminer avec l'accord des soignants doit satisfaire aux dispositions de la loi Leonetti, qui valide le refus de l'obstination déraisonnable et aménage pour l'essentiel une possibilité de faciliter la survenue du décès, l'interruption de l'alimentation et de l'hydratation. Cette faculté serait aujourd'hui plus souvent utilisée en France que ne l'imaginaient ses promoteurs. Mais force est de constater que cela entraîne des moments difficiles, voire ressentis comme « indignes », se prolongeant une semaine voire au-delà. Cette modalité s'avère plus bouleversante, pour proches et soignants, que ne le serait un geste bref mettant un terme à l'existence. Pour Fournier, l'argument théorique sous-tendant la loi (laisser mourir, d'accord, mais faire mourir, jamais) a dans la réalité certains effets déplorables. Elle plaide pour que soit reconnu que, souvent, la différence entre les deux est ténue, discutable. Et qu'un geste permettant le décès sans de tels délais devrait être acceptable - et cas écheant préféré. Distinguo d'importance : « Le législateur a choisi en 2005 d'autoriser l'arrêt d'alimentation et d'hydratation mais d'interdire l'injection létale. Le choix est respectable. Encore faudrait-il qu'il soit compris dans ces termes par nos concitoyens, c'est-à-dire comme un compromis plutôt que comme une vérité éthique. »

Le combat de Véronique Fournier, courtois, sans amertume même si les réalités rencontrées sont frustrantes, c'est de montrer qu'on se paie de mots avec la « mantra » du « non à l'obstination déraisonnable, auquel cas on peut laisser mourir » couplée au « jamais il ne saurait être question de faire mourir ». Les frontières sont objectivement fragiles et ce n'est qu'au prix de constructions doctrinaires, à

distance de la vie des gens, qu'on s'emploie à maintenir un clivage prétendument absolu. Ce qu'elle explique devrait contribuer à convaincre ceux qui souhaitent des politiques publiques qui soient équilibrées dans ce qu'elles autorisent ou au contraire interdisent à leurs citoyens.

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**Robert Holcman**  
**Inégaux devant la mort – « Droit à mourir », l'ultime injustice sociale**  
**Paris : Dunod, 2015, 200 pages**

Economiste et gestionnaire français, ayant assumé des tâches dirigeantes en hôpital, enseignant, Robert Holcman publie un ouvrage dense sur l'éventail des facettes du thème « fin de vie et droit à mourir » qui fait beaucoup débat aujourd'hui. On y trouve la matière de beaucoup de prises de position et de débats sur ce sujet, ce qui peut faire de ce livre une référence utile. Une référence toutefois que salueront surtout ceux qui restent très réticents, voire fondamentalement opposés à la libre détermination des personnes dans ce domaine.

Souvent, l'ouvrage laisse une impression de théorie, d'invocation de principes qu'on voudrait figés alors que tout change. Ce qui ne rend pas justice à ce que sont aujourd'hui nos sociétés et leurs systèmes de santé : l'évolution démographique (« tsunami gris »), les pathologies principales et leur chronicité, le fait que le citoyen entend être autonome, y compris au plan des soins qu'il demande et reçoit. Il ne s'agit pas ici de dire que tout ce qui valait ne vaut plus, mais d'accepter la confrontation avec les réalités vécues et d'y réfléchir éthiquement - dans le sens de rechercher « comment faire pour bien faire ».

Une chose frappe dans le panorama brossé par l'auteur : on n'y trouve pas de récits cliniques, d'histoires de patients qui fassent toucher du doigt ce que vivent, en France aujourd'hui, les malades en fin de vie, leurs proches et les soignants. On est surtout confronté à des argumentations intellectuelles. Bien sûr, il importe de rappeler ce que les sociologues, les philosophes ou des instances officielles ont dit sur ces sujets. Mais il faudrait faire la part de ce qui est options dogmatiques, parfois répétées encore et encore, et de ce qu'on sait pratiquement. Le rapport de la Commission Sicard présenté en décembre 2012 a été limpide dans sa conclusion : « en général, on meurt mal en France aujourd'hui et il est urgent d'améliorer la situation ». Pour cela, le développement des soins palliatifs est à l'évidence une avenue majeure mais ne

saurait être l'entier de la solution. Au-delà, trois ans plus tard, « Inégaux devant la mort » ne suggère pas d'avancée notable ; l'auteur dit même à plusieurs reprises ses réserves à l'endroit de la révision récente de la loi française dite Claeys Leonetti qui admet la sédation terminale.

Point d'importance : s'agissant d'inégalité, l'auteur rappelle à juste titre la constante, qui préoccupe fondamentalement les professionnels de santé publique (et doit préoccuper les politiques), des inégalités dans l'accès aux soins pour les groupes moins favorisés, leur plus grande morbidité et leur moindre espérance de vie. Il craint que, dans la foulée, les personnes précarisées soient poussées plus que d'autres à envisager de mettre fin à leurs jours - cas échéant en y étant incités par leurs proches pour des motifs matériels. Préoccupation tout à fait estimable (comme l'est, plus généralement, la crainte que des mesures d'économies au sein du système de santé soient au détriment des patients). Toutefois, si ce souci se comprend bien dans un pays comme les Etats-Unis où l'accès aux soins reste fort inégalitaire, c'est moins le cas en France où un système de santé social et étoffé doit assurer à tous une prise en charge adéquate.

Clairement, la grande différence entre Holcman et d'autres (dont le rédacteur de cette recension) est dans l'importance et le respect accordé à l'autonomie de la personne. Il y a dans le livre une réticence palpable à admettre que les patients ont le droit de décider de leur propre existence, y compris quant à l'option de lui mettre un terme quand elle est devenue trop lourde à porter. On peut, on doit bien sûr avoir le souci que ces décisions soient bien réfléchies mais cela ne saurait justifier le retour à une posture paternaliste, élitiste. Posture où ceux qui sauraient mieux (?) pourraient contester la compétence de la personne lambda et la légitimité de ce qu'elle décide ? La société est faite de beaucoup de personnes lambda, qui doivent être vues comme adultes et majeures. Parlant d'enjeux de santé, de maladie et d'éthique, on ne peut accepter des raisonnements répétés tendant à disqualifier les patients qui ne pensent pas comme soi, dont l'avis serait forcément peu crédible s'ils sollicitent une aide au suicide. En 2015, près de quinze ans après la loi Kouchner sur les droits des malades, il y a là un anachronisme grave, ou de la cécité.

A propos du titre du livre : il y a une inégalité, différente de celle qu'argumente l'auteur, qui au plan citoyen n'est pas admissible : la réalité qu'un statut social plus élevé facilite pour qui le souhaite d'avoir accès aux moyens de terminer sa vie. Qu'il suffise de rappeler que Mme Jospin, mère d'un premier ministre, a pu bénéficier d'une aide au suicide - qui n'a guère suscité

de réprobation sociétale. N'y a-t-il pas lieu, au pays des droits de l'homme, de s'émouvoir de tels écarts, au détriment de la libre détermination des moins influents ? A cet égard, Holcman évoque le fait indiscuté qu'il y a, en France et ailleurs, un nombre notable d'assistances au suicide et d'euthanasies qui ne disent pas leur nom. Il les regrette mais semble s'accommoder de cette clandestinité. A notre sens, le fait choquant que ces choses soient tolérées sous le manteau enlève beaucoup au poids d'argumentations dogmatiques refusant de considérer dans la clarté une évolution sociétale profonde, à propos de quoi des pays voisins de la France, vus généralement comme civilisés eux aussi, ont décidé de reconnaître l'autonomie des personnes - ce qui n'empêche pas bien sûr de le faire en mettant en place des garanties adéquates.

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## ANNOUNCEMENT

**Big Data, Ethics and the Market**  
**Monday 20 June 2016, 09:00 – 17:30,**  
**St Anne's College, Oxford**

The translation of genomic medicine from basic research into medical practice involves partnership of public sector and private companies. Recent empirical research demonstrates that public attitudes towards commercial interests in healthcare are, at best, hesitant. Importantly these attitudes involve significant ethical and conceptual claims and presuppositions about the ethics of markets and the relationship between markets and other areas of value, specifically health and health care.

The Centre for Personalised Medicine and the Ethox Centre of the University of Oxford are hosting a conference that will explore how a publicly funded healthcare system can optimise partnerships with the commercial sector in using data to improve patient outcomes, whilst maintaining its central principles of patient care.

The event will be introduced by **Peter Donnelly** (Wellcome Trust Centre for Human Genetics, University of Oxford).

**Confirmed speakers** include **Adrian Walsh** (School of Humanities, University of New England, Australia), **Natalie Banner** (Wellcome Trust), **Steve Sturdy** (School of Social and Political Science, University of Edinburgh), **Mark Bale** (Genomics England), **Sir Rory**

**Collins** (UK Biobank) and **Gil McVean** (Big Data Institute, University of Oxford).

For more information and registration:

[http://www.oxforduniversitystores.co.uk/browse/extra\\_info.asp?compid=1&modid=2&deptid=135&catid=106&prodid=490&searchresults=1](http://www.oxforduniversitystores.co.uk/browse/extra_info.asp?compid=1&modid=2&deptid=135&catid=106&prodid=490&searchresults=1)

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