

EACME Newsletter

European Association of Centres of Medical Ethics

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EDITORIAL

TS Eliot's poem *East Coker* is interpreted by many as an imprecation to reduce societal obsessions with the pursuit of scientific progress and to instead follow simpler, more diurnal lives of spirituality and contemplation. Philosophically this view raises questions for medical ethics. How or should medical ethics hold the line against a scientific view of enlightenment? Should we defend a less rationalistic view of humanity, despite this being a place where superstition and ignorance might prevail (with all that entails)? Even if we take a more analytic approach to science, how far should ethicists check the hands of scientists lest their dreams create monsters? And how much are we compromised in our pursuit of these goals? Medical ethics itself is of course bound up with this desire to create and renew. It is in no small part due to a relentless pursuit of scientific growth that ethicists find a stable niche in universities and hospitals – indeed, the way funding is structured often compels career minded researchers to pursue the newest technologies on the block. So in some part our activities may involve making sure scientific progress is matched with similar progress in ethics. This is no small task, if indeed such a goal is even possible – good ethics is hard work, and despite our stable niche, there are not so very many of us.

This issue of the EACME newsletter deals both with the what is new in science and what is new in ethics. Not only do we hear from Andoh Cletus Tandoh about ethical concerns raised by scientific progress in human genome editing in the African context, but we carry reviews of several works that propose ethical innovations designed to address the challenges raised by modern medical and scientific progress. Marie Gaille writes a fulsome review of past EACME president Ruud ter Meulen's great work on the ethical principle of solidarity, which is aimed at addressing the gaps left by

current ethical theories of justice; Among several fine articles by our stalwart contributor Jean Martin, we have a review of Marta Spranzi's new book discussing the role of moral intuitionism in the clinic. We also hear about innovations in our own network. As some may know, at the last EACME conference at VUMC in Amsterdam we had the satellite meetings of two new networks that have grown from our association. For those who have not heard of these, we carry reports from the European Clinical Ethics Network and the Cambridge Consortium of Bioethics Education. I hope you find these articles provide some interesting pre-Christmas reading!

Giles Birchley, Editor, EACME Newsletter

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NEWS FROM THE EACME BUREAU

Dear colleagues and friends,

We hope this Newsletter finds you well. This time we as Bureau, would like to focus on the relatively new EACME Collaboration Prize.

We are constantly looking for ways to foster collaborations within our association. EACME offers a unique platform to stimulate professional exchange and create new opportunities for collaboration within the field of medical ethics. Our new prize (up to 1000 Euros) was created in order to encourage collaborations between member centres who would like to e.g. co-organise workshops or work on a joint grant application. Collaborations can create continuous learning opportunities, growth and development, and strengthen our EACME community. Deadline: 1st of March. Curious? Please find more information [here](#).

Furthermore, we would like to draw your attention to the already well established EACME visiting scholarship exchange programme. The exchange with other EACME centres across Europe allows young researchers to broaden their personal and scientific horizons, which will enrich their academic vision. Eligible for the EACME visiting scholarship are master students, PhD students and early post-docs from EACME centres who would like to visit another EACME centre.

EACME contributes 1000 Euros to the exchange programme. This year we will have 2 visiting scholarships available!

Deadlines: 1st of March and 1st of September.

Terms and conditions: Please find more information [here](#).

Let us join forces in the further development of these networking tools and let them flourish!
Seasonal greetings from the EACME Bureau to you and your loved ones. May 2019 be full of prosperous ideas, academic exchange and success!

Rouven, on behalf of the Bureau (Ruth, Bert and Angelique)

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INTRODUCTION TO THE EUROPEAN CLINICAL ETHICS NETWORK: ECEN (FOUNDED 2005)*

** Most of this text is based on the following paper: Molewijk, B, A Slowther, J Schildmann (2016). The European Clinical Ethics Network (ECEN): the professional development of clinical ethics support in Europe and the role of evaluation thereby. Bioethica Forum, Vol. 9, nr.2, p. 86-89.*

Following the second International Conference on Clinical Ethics Consultation (ICCEC) meeting in Basel in 2005, a group of European clinical ethicists founded the European Clinical Ethics Network (ECEN) in order to have more specific time for deliberating on developments in the various clinical ethics support services in Europe. ECEN at that time was an informal working group of clinical ethics scholars from European countries with both practical experience in developing and providing clinical ethics support services and research interest and experience in the field of CESS. At that time, the main goal of the network was to explore in detail how clinical ethics case support services are carried out in various European countries and to exchange experiences in order to learn from each other. Later, a second goal of the network became to foster and further professionalize CESS (e.g., by means of exchanging experiences with colleagues outside ECEN and by means of education and research). A third goal became to put CESS more on the European agenda, both in various health care domains and in training and scientific research.

The ECEN usually meets once a year during both a 'closed' meeting for ECEN members only and an ECEN Open Forum Day for anyone interested in CESS. These meetings are usually combined with the EACME conferences. Each ECEN meeting consists of a number of clinical and research presentations, usually around a central topic (e.g., patient participation in CESS, CESS and the media, CESS and evaluation research, CESS and priority setting). Several working groups have been established with focus on specific topics and to report to ECEN later on their activities and results. This resulted among others in a thematic issue in Clinical Ethics on

CESS and patient participation (2009) and CESS in mental health care (2016). A list of ECEN and CESS related papers from the ECEN members are visible on the ECEN website: www.ecenetwork.org

In order to share the coordinating activities, to make various ECEN policy issues more transparent and to foster the future development of ECEN, an ECEN Steering Group has been founded in 2012 (current members: Silviya Aleksandrova, Cristina Gavrilovici, Bert Molewijk (coordinator), Gerald Neitzke, Anne Slowther). At this moment the ECEN has 30 members from the following 20 European countries: Austria, Belgium, Bulgaria, Denmark, Great Britain, Croatia, Finland, France, Germany, Hungary, Italy, Moldavia, the Netherlands, Norway, Romania, Serbia, Spain, Sweden, Switzerland and Turkey.

Prof. Bert Molewijk (VUMC Amsterdam),
Dr. Anne Slowther (University of Warwick) and
Prof. Jan Schildmann (University Hospital Halle)

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THE CAMBRIDGE CONSORTIUM OF BIOETHICS EDUCATION

The Cambridge Consortium of Bioethics Education was established by Cambridge University Press in 2011. The Platform mainly aimed at developing bioethics education through annual meetings in Paris, bringing together bioethics educators around the world to share experiences and ideas on developing curricula and teaching methods.

A Network of Country-based Cambridge Bioethics Education Working Groups

The Consortium initiated country-based Working Groups, from 2013 on, to encourage people and institutions to work together on developing bioethics education in their countries. Coordinators of the Working Groups form a Network which meets twice a year. Aims of the Network are to foster bioethics education, by exchange of information and collaboration within and between national Cambridge Consortium of Bioethics Education Working Groups. The focus of exchange and cooperation is on teaching content, methodology and organisation, in line with the objectives of the Cambridge Consortium on Bioethics Education.

Structure

The network participants are coordinators of national Cambridge Working Groups. For each country, one participant is member of the board of the network. The executive board of the network consists of Guy

Widdershoven (President), Yesim Isil Ulman (General Secretary), Vojin Rakic (member) and Peter Kakuk (member). In the meantime, Yolande Voskes, Volkan Kavas, Emanuele Valenti, Marielle Diepeveen, Matthew James and Rouven Porz have been contributing to the Cambridge Network by attending Cambridge Consortium Paris meetings or the interim meetings. The Network is open for new active members.

Members

Bosnia-Herzegovina, Britain, Germany, Hungary, Italy, New Zealand, Pan-Arab countries (Lebanon), Portugal, Romania, Russia, Serbia, Spain, Switzerland, the Netherlands, Turkey; the United States and Canada across the Atlantic.

Activities

- The network meets two times a year, including the Paris Consortium meeting.
- The activities focus on exchange of information on content, methods and organization of bioethics education.
- A comparative study is planned on teaching methodology and content among the countries.
- Cooperation has resulted in a project aimed at implementing Moral Case Deliberation in Turkey.
- New EU projects VIRT2UE (Guy Widdershoven, Amsterdam) and ALCMEON (Emanuele Valenti, Madrid) provide opportunities for participation of members.

Network Activities

- **Cambridge Bioethics Education Network Interim Meeting I: Amsterdam VU medical center, Dep. of Medical Humanities, January 2015**

Representatives of country WG's from Hungary, the Netherlands, Serbia, Switzerland and Turkey came together to exchange experiences and explore the opportunities for mutual, multi-centered research for the WG's in the Cambridge Consortium of Bioethics Education.

Cambridge Bioethics Education Network Interim Meeting II: Istanbul Acibadem University School of Medicine, January 2016

Representatives of country working groups of Hungary, Lebanon, the Netherlands, Serbia, Spain and Turkey came together to exchange best practices on teaching bioethics (incl. Moral Case Deliberation, case-based ethics teaching, use of cinema in ethics education, skills training for informed consent) and to discuss future collaboration.

Cambridge Bioethics Education Network Interim Meeting III: Department of Behavioral Sciences in Debrecen University, December 2016

The Representatives of country WG's from Hungary, the Netherlands, Turkey and Spain participated in the meeting. Exchange of best practices took place through oral and poster papers and a Moral Case Deliberation session.

An Example of activities in a Cambridge Bioethics Education Working Group: [Turkey](#)

The Turkey WG is based in Istanbul Acibadem University. The aim is to raise awareness in and enhance advocacy of ethics education in health sciences education in Turkey. The WG arranged the following activities:

- 10 local workshops have been organized.
- Group representatives regularly attend the Paris Consortium meetings and submit annual activity reports.
- The Group introduced itself by a paper and conducted a workshop on "Can ethics be taught?" at the 2nd Conference of International Association of Ethics Education, Ankara, 2014
- Two articles were published in the Turkish Journal of Bioethics.
- The Group has initiated a curricular inventory study on bioethics education all over Turkey. Data sharing stage has been completed and the Group has prepared writing the article.

A New Initiative: EACME Satellite Meetings

Instead of organising ad hoc interim meetings between the Paris meetings, the Cambridge Network decided in 2018 during the Paris Consortium meeting to initiate satellite meetings of EACME Conferences in order to get in touch with more ethics educators. The first satellite meeting was realized on the eve of EACME Amsterdam Conference on September 5-6, 2018. The next will take place in Oxford, September 2019.

Contact Info:

If you are interested in taking part in the Cambridge Network, please get in touch with Guy Widdershoven g.widdershoven@vumc.nl & Yesim Isil Ulman yesimul@yahoo.com

Acknowledgement

The Working Groups, collaborating under the umbrella of the Cambridge Consortium of Bioethics Education, are thankful to Prof. Dr. Thomasine Kushner for her leadership and enthusiasm in supporting country Working Groups.

Yesim Isil Ulman¹ and Guy Widdershoven²

1. Acibadem University, Department of History of Medicine / Bioethics
2. Amsterdam VU medical center, Dep. of Medical Humanities

Sources:

- Yolande Voskes, Yesim Isil Ulman, Menno de Bree, Kevser Vatansever, Mariëlle Diepeveen, Guy Widdershoven, "The Cambridge Bioethics Education Working Groups Network: aims and experiences", AMEE, An International Association for Medical Education, 27-31 August 2016, Barcelona, Spain. Abstracts Book, p. 691.
- Ulman YI et al (Turkey Working Group Members), "Cambridge Consortium of Bioethics Education Turkey Working Group", Turkish Journal of Bioethics, 2014; 1(4):184-7.

HUMAN GENOME EDITING: POSSIBILITIES AND CHALLENGES FOR AFRICA

Cutting-edge genome editing technologies offer enormous health and therapeutic prospects for treatment of infertility and eradication of devastating inherited human diseases, suffering, and disability afflicting millions of Africans, but with unknown risks to health and well-being. Despite the fact that genome editing creates challenges about choices to alter the genomes of future generations and implications for our common humanity, a critical review of literature reveals that the framing and shaping of the central issues on the science, ethics and regulatory governance are exclusively based on the framework of Western principles and values. An authentic African assessment of the development, application and evaluation of potential benefits and risks is still lacking. African countries lack the knowledge required to guide strict clinical oversight, credible pre-clinical data on risk and health benefits, and the assurance of long-term multigenerational follow-up. Serious discussions on the ethics of embryo-editing research seem to have blunted the controversial edge of gene editing technology CRISPR–Cas9. Currently, there is a huge knowledge gap about the technique with human embryos, absence of oversight mechanisms, institutional, procedural and professional capacities to enhance quality, safety and ethical propriety of research in Africa. I explore the scientific possibilities, regulatory challenges and critically evaluate the ethical and social concerns by questioning if the idea of tailor-designing a human person with a view to remaking humanity distorts our understanding of what it means to be human. I further argue for the need for more inclusive dialogue and engagement to enhance global responsible research.

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2018/2019

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SHORT SUMMARY OF THE EVALUATION OF EACME AMSTERDAM: ETHICS IN ACTION 2018

Time flies! On the 6th to 8th September we had the 35th EACME conference in Amsterdam, organized by the department of Medical Humanities from Amsterdam Medical University Centers (location VUmc). We received 113 evaluation questionnaires from exactly 200 participants: thanks for those who filled in the questionnaires! The information received informs us how the participants experienced the EACME conference in Amsterdam, what kind of people participated and also what the participants would like to focus on in next EACME conferences. A brief impression of the participants: most of the participants were researchers (ranging from research assistant and PhD student to professor) and only approximately 10% were clinicians, care givers or spiritual care givers; 25% were EACME member and 75% not; about 45% participated for the first time in an EACME conference, about 45% 2 to 6 times, and some participated 20 or even 28 times; 10% participated also in the satellite meeting of the European Clinical Ethics Network (ECEN) on the 5th of September. Overall the conference was rated with approximately 4.1 on a scale from 1 to 5 (ranging from 3.68 to 4.35); with higher rates for content, facilities and organization, and somehow lower rates on catering. Lunch and welcome drinks. The plenary sessions were rated with 3.6 to 4.2. Overall, this means that for those who filled in the questionnaire: the Amsterdam conference was rated good.

Based on the open answers about what participants liked and what could get improved the next time, we learned, as announced in the opening session: 'the ethics of organizing an ethics conference', that there is no ideal EACME conference... Some really liked the ethics in action with lively interactions on concrete cases and would even have seen more in future EACME conferences; others found it too applied, too concrete, too much attention for Amsterdam's research topics and missing other bioethical themes. Some comments (out of 64 comments) related to what people liked the most: *'Positive culture of Dutch hosts, humour; greatest hospitality; the spirit of friendliness and collaboration; the variety of items faced during the parallel sessions; and involvement of real patients'*. Things for improvement (out of 61): *'practical training and application of the theory; more time for confrontation*

and discussion; catering; too many parallel sessions; more attention for PhD students; include more patients and clinicians/care –givers'. Finally, for future EACME conferences, some participants (out of 25 suggestions) plead for: *'more attention to new medical and biotechnologies, justice in health and social care, migrants and cultural issues; sessions on opportunities and challenges of publishing in bioethics; relationship between academia and activism; ethics in the face of global risks towards humanity (wars, humanitarian crises, natural disasters, militarism, racism, exploitation, etc)'*.

Thanks for coming together in Amsterdam and share your work in ethics! See you in Oxford next year.

On behalf of the organizing team,

Bert Molewijk

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CLINICAL ETHICS CONSULTATION AND COERCION: ANALYSIS OF COERCION IN A SWISS UNIVERSITY HOSPITAL

Ever since I took part in a conference on coercion at the Rizzoli's Hospital in Bologna and at the EACME conference in Barcelona last summer, I became interested in the activity of Professor Reiter-Theil and her team in Basel/Switzerland.

Supported by Professor Picozzi and the University of Insubria (Varese) I was kindly allowed to do research abroad; I spent more than four months, between March and July 2018, as a PhD student in the Department of Clinical Ethics in Basel. My study was supported by 1,000 euro visiting scholarship grant from EACME fellowship, which offers young researchers with original and well structured projects the funds to carry them out abroad in order to publish paper and articles which may be part of their thesis. Every year the EACME fellowship scheme selects only the project of one PhD student and for 2018 my application was successful. In Basel I was able to participate in different sectors of continuing Ethics Education for doctors and nurses, and even in Ethics Consultations taking place both in the (somatic) University Hospital and in the University Psychiatric Hospitals, Basel.

My main interest was to work with the Basel Database of Ethics Consultation (SPSS) and to explore in what way coercion featured in ethics consultations. I was given the opportunity to work especially with one (published) sample of 100 systematically documented ethics consultations, of which 24 deal with the theme of

coercion. It was agreed to prepare a collaborative publication co-authored by Elena Montaguti, Jan Schürmann, Charlotte Wetterauer, Mario Picozzi, Stella Reiter-Theil. This is being prepared and will be entitled *The role of Ethics Consultation in Coercion*.

However, besides the products of my stay in Basel, I really appreciated the engaging attitude of Stella Reiter-Theil and her interdisciplinary team. Although everybody worked on his or her own questions and papers, I felt connected to everybody through inspiring and interesting talks. Altogether everybody transmitted their passion for their subject and their desire to work in a team.

Last, but not least, it should be mentioned how easy it was for me to find the resources I needed for my work. The possibility to use all the research infrastructure (including the Database) and literature was carefully organized for me. I hope I will return to Basel, be it to find more sources for my dissertation thesis or to engage in a possible future collaboration.

My message to readers would be: I recommend the Department of Clinical Ethics in Basel to everybody interested in doing research on the topic of Clinical Ethics and especially to those researchers who would really like to carry out high quality interdisciplinary research.

I also recommend the UB University Library in Basel with its variety of interesting sources that are fundamental for drafting a thesis, as well as the beautiful view of the Rhine from the main church, the museums and the art galleries of the city.

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NEW ASSOCIATE MEMBER

New Opportunities

Vienna calling - a new era of exchange? Professor Barbara Prainsack launches her Centre for the Study of Contemporary Solidarity (CeSCoS) at the University of Vienna

Attended and Reported by
Saheli Datta Burton (Visiting Fellow, CeSCoS) and
Katharina Kieslich (Research Fellow, CeSCoS)

Professor Barbara Prainsack launched her Centre for the Study of Contemporary Solidarity (CeSCoS) in Vienna on the 15th November 2018. CeSCoS is the newest addition to the Department of Political Science at the University of Vienna and has already gathered an impressive team of early-career scholars and PhD students from internationally renowned institutions committed to advancing the contemporary understanding and relevance of the concept of *Solidarity* in research and practice. The aim of the group is to take the dust off this allegedly outdated concept and fill it with new life; the group believes that solidarity has much to offer to address some of our most pressing societal challenges. The day-long launch event on 15 November showcased this through talks by members of CeSCoS and by renowned international scholars on CeSCoS' advisory board.

The event - aptly titled 'Solidarity in research and practice – why now?', aimed to reinvigorate a discussion on the use of the concept of solidarity in contemporary politics, policy, and other domains of practice. This was highlighted by Professors Barbara Prainsack's and her close collaborator and CeSCoS non-executive co-director Alena Buyx's (Technical University of Munich) introductory speech which argued that solidarity could give concrete guidance for policy and practice. If defined clearly and distinguished from other types of prosocial practice, the speakers argued, solidarity could serve as 'an organising principle for policies and institutions, to address key societal challenges such as the reform of healthcare systems and the increase of social disparities'. Barbara Prainsack then gave concrete examples such as the use of solidarity-based governance in the context of digital data governance. The organisers of the event also encouraged discussion and debate around CeSCoS' conceptualisation of *solidarity*, in particular also in relation to concepts and issues of social justice, reciprocity, altruism, and relational autonomy.

The morning and afternoon sessions (9.30am-4pm) featured multidisciplinary talks on the human rights (or its lack of) implications of the multi-layered interpretations and tensions of solidarity at transnational level (Professor Carol Gould, City University NY), the need for greater state intervention to enhance distributive and social justice (Professor Linsey McGoey, University of Essex), solidarity in the current patient rights paradigm (Professor David Townsend, Maastricht University), and enactments of solidarity in real-life contexts (Bernard Dichek, filmmaker, Israel). A panel discussion on '*Why do we need Solidarity?*' chaired by Dr Katharina Kieslich (University of Vienna) unleashed a lively and controversial debate around the possibility of a solidarity with and for all of humanity. The second part of the day, which took place in German to be accessible also to a local audience, began with a

welcome address by the Vice Rector of the University of Vienna, Professor Christa Schnabl followed by an inspirational keynote speech from Dr Auma Obama, Founder and Director of the Sauti Kuu Foundation. Sauti Kuu seeks to give a voice to financially and socially disadvantaged children and youth in Kenya and other countries on the African continent. Finally, Peter Dabrock, Professor at the Friedrich-Alexander-University Erlangen-Nuremberg, and Chairperson of the German Ethics Council, rounded up the day by speaking about the role of solidarity in the digital age. The ensuing discussion focused on the role of conflict in promoting, or hindering, solidaristic practice in the 21st century.

CeSCoS is a proud new member of EACME and the group looks forward to exchanges and collaborations with fellow EACME members.

Links:

CeSCoS website:

<https://politikwissenschaft.univie.ac.at/en/research/main-areas-of-research/centre-for-the-study-of-contemporary-solidarity-cescos/>

Recent special issue of BIOETHICS on solidarity (ed. Alena Buyx & Barbara Prainsack:

<https://onlinelibrary.wiley.com/toc/14678519/current>)

BOOK REVIEW - Marta Spranzi «Le travail de l'éthique - Décision clinique et intuitions morales»

Philosophe des sciences italiennes formée aussi en France et aux Etats-Unis, Marta Spranzi enseigne au plan universitaire et est chargée de mission au Centre d'éthique clinique de l'Assistance publique – Hôpitaux de Paris. Son ouvrage est un argumentaire substantiel pour une approche résolument *bottom up*, inductive, du travail bioéthique, qu'elle dit heuristique - contrastant avec une démarche *top down*, qu'elle appelle rhétorique, parfois éloignée des faits. « Le but de l'éthique, dans sa dimension existentielle – par opposition à hiérarchique – est de donner forme à ce qui compte dans notre vie. »

En soi, on voudrait des normes emportant l'approbation de tous. Mais « il n'y a pas à espérer des spécialistes de la normativité des solutions toutes faites : ils ne peuvent que proposer une palette de perspectives largement divergentes » - au vu des différences culturelles et religieuses. Devant ce pluralisme irréductible, Spranzi propose de partir des situations particulières pour trouver ce qu'il est mieux de faire. « Le socle de la vie morale n'est pas un système déductif commandé par des principes, il est constitué par des intuitions qui sont au centre de notre expérience

morale. C'est un socle mouvant, sensible aux raisons, il n'en joue pas moins un rôle fondateur essentiel. »

« La seule façon de réfléchir constructivement à la bioéthique est de s'assurer d'une évolution adéquate des normes et de partir des dilemmes réels auxquels les personnes concernées doivent faire face (...) L'expérience morale des personnes est la pierre de touche de cet édifice complexe qu'est l'éthique clinique. » Au lieu d'attendre le salut du débat normatif en haut lieu, on s'intéressera à la façon dont les décisions critiques sont prises et dont les valeurs des uns et des autres sont négociées au quotidien. Spranzi met l'accent sur l'expérience morale par opposition au jugement moral.

Cette éthique heuristique tire donc parti des valeurs des personnes concernées, patients, proches ou professionnels de santé. Ni consensus ni compromis, la bonne décision est celle qui, dans le contexte, apparaît aux participants comme la plus acceptable – ou la moins mauvaise. Pratique du registre empirique et démocratique, défendant une forme d'intuitionnisme moral critique - consistant à accorder du crédit à des apparences intellectuelles (*seemings*) fortes obtenues de façon non inférentielle. « Une approche heuristique a aussi un intérêt politique au sens large et concerne directement la nature et le rôle de la médecine. Ce sont les citoyens en tant que patients qui sollicitent les professionnels et secouent les pratiques. Leur voix – et non seulement leur consentement – est une pièce essentielle de ce puzzle compliqué qu'est la décision médicale. »

Concrètement, dans les soins (*care*), « le travail d'ajustement progressif des pratiques est très utile et repose sur des valeurs non controversées. En se concentrant sur le 'comment faire' plutôt que sur le 'que faire', on privilégie l'opérationnalité. Toutefois, cette démarche est impuissante à traiter les cas 'qui fâchent'. La conception alternative que je défends part de la reconnaissance des conflits de valeurs, pour déployer leurs raisons et identifier les solutions possibles. »

L'art est de trouver la « bonne » – ou moins mauvaise – décision dans les cas singuliers. « Dans cette perspective, les conflits de valeurs ne sont pas un obstacle qui doit être esquivé mais plutôt un outil de travail essentiel (...) La contestation est inscrite dans la démarche éthique elle-même et ne constitue ni une exception ni une situation à laquelle il faudrait remédier. » Cette démarche « s'appuie donc sur le dissensus ; elle ne se veut pas d'emblée apaisante mais joue le rôle inconfortable de 'poil à gratter', au sens de mise à l'épreuve des raisons des uns et des autres. » Un arbitrage est alors nécessaire.

Le propos est illustré par des situations cliniques, en particulier celles du musicien et de l'ingénieur - deux cas tout à fait similaires du point de vue médical (*locked-in syndrome*) où les réflexions et décisions, entre équipes et proches, ont été différentes. Elle consacre une section du chapitre 3 aux questions entourant la fin de vie, discutant des cas qui ont retenu l'attention en France, ainsi que le Rapport Sicard de 2012 et la loi Claeys-Leonetti de 2016. Elle commente dans ce cadre la notion d'intentionnalité, qui dans les faits garde des contours flous.

Le quatrième et dernier chapitre est une présentation des philosophes qui ont fait des intuitions leur champ d'étude et de leurs travaux. Spranzi y débat d'intuitionnisme élitiste et d'intuitionnisme démocratique, des critiques faites à cette doctrine et des réponses qu'on peut leur donner. En développant l'hypothèse qu'une approche heuristique doit inclure un processus de tri des intuitions. Noter encore cette remarque : « Les utilitaristes, qui sont les représentants les plus anti-intuitionnistes, s'emploient à lutter contre l'emprise de tout jugement spontané et immédiat. »

Chacun serait-il un expert en éthique ? « Tout le monde possède potentiellement l'expertise morale nécessaire pour réfléchir et faire face aux dilemmes éthiques. ». Toutefois : « Faut-il admettre alors que le rôle des experts éthiques est purement pédagogique ? Nullement : si les personnes concernées peuvent faire valoir une expertise sur la base de leurs intuitions morales, cela n'empêche pas que le rôle de tiers joué par le consultant reste essentiel dans les situations de conflits de valeurs. »

Le livre de Marta Spranzi est important en ceci qu'il met substantiellement en discussion, en éthique, la place des intuitions, définies comme des « jugements à la fois immédiats, résistants à la critique et stables dans le temps ». Alors que prévaut souvent la notion qu'il s'agit d'abord de suivre un cadre de règles, dans une démarche *top down* (la règle dit ceci, il s'ensuit que...). Il est nécessaire de travailler dans les deux sens, à savoir aussi *bottom up*. L'auteure « rejette une dichotomie entre le monde naturel que nous habitons, le monde des faits, et un autre monde, celui des normes - la moralité n'entre pas dans le monde en provenance d'un 'ailleurs'. »

Dr. Jean Martin

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BOOK REVIEW - Ruud ter Meulen, *Solidarity and Justice in Health and Social care*

In this book, with outstanding clarity, Ruud ter Meulen tackles a crucial, but complex and delicate issue, for both political and moral philosophy and policy-making in health care. His ambition is to answer a question raised by Illigworth and Parmet in 2012: 'what does solidarity offer that other ethical concepts, such as justice, communitarianism, egalitarianism, or even altruism, do not?' ('Solidarity for Global Health', *Bioethics*, 26(7), pp. ii-iv). In doing so, he also intends to formulate the specific contribution of solidarity as a moral principle to policy-making in health care.

This ambition is not self-explanatory. It actually takes place in a specific context. To grasp this context, one needs not to remain entrenched in a monolithic vision of political theory and decision-making. Rather, one has to acknowledge various facts: for at least two centuries, there have been various contributions to the conception of what people owe to each other; ideas and norms have a situated history; their content may evolve; they travel from one society to another; and finally, there are significant variations in their assessment through space and time. Ruud ter Meulen's reflection is thus embedded in a (mainly) Western context, in which "the idea of solidarity played an important role in many social movements in the past two centuries" (p. vii), but has been recently put in doubt and confronted with competing concepts, particularly that of justice. This is observable both in bioethics and in political and moral theory, as well as in political decision-making, to varying degrees in various places. In this context, another key element to understand Ruud ter Meulen's enterprise is the discussion about the meaning and implications of individual autonomy. Seen as the highest value to be promoted, it will be frequently associated with the vocabulary of justice; seen as opening a door to egoism, it will frequently be criticized on behalf of a relational conception of autonomy emphasizing human ties, cooperation and interdependency, and thus solidarity.

In order to answer the questions of what solidarity may offer today and of which specific role it may play in health-care policy-making, Ruud ter Meulen embarks the reader on a journey organised in the following way: as "solidarity is a concept with many layers and meanings due to its various ideological backgrounds, moral traditions and disciplinary understandings" (p. 29), the first task to be fulfilled is that of clarification based on various tools: history of ideas, conceptual analysis, interdisciplinary approach. After dedicating a chapter to this first step, he enters the heart of the discussion about the compared meaning and scope of the notions of solidarity and justice (chapter 3). In this discussion, he

does not only remain at the level of a general political theory. In chapter 4, he examines the role of solidarity in health-care policies in the specific case of Dutch health-care. This is not just an “illustration”. Rather, this analysis allows the reader to understand how solidarity is referred to at the level of policy-making. Then comes an essential chapter to us, dedicated to informal care-giving or family care (chapter 5). At a factual level, it offers a very interesting and complementary analysis of care in the private sphere. It is based on the conviction that if one neglects this sphere as non-political, one misses a crucial puzzle piece to understand how solidarity actually manifests itself in society: not only through state organised policies, but also through private relationships. In addition, this observation has also implications for policy-making. According to the author, both spheres, the private and the public ones, must not be considered separately. Informal care-giving and family care need institutional and professional support (nurses, paramedics, home help and day care centres).

Focusing on these examples of informal care-giving and family care, the 5th chapter lays the foundation for the normative approach developed in the 6th and last chapter, in which Ruud ter Meulen states his position about solidarity and justice, and their respective role in health care policies. He does so by answering five “claims”: the first relates to the vision of solidarity as grounded on factual data; the second affirms that justice is enough to analyse and understand normative obligations in modern societies; the third questions the role of the state in the development and support of solidarity in society; the fourth asserts that ‘solidarity will inevitably result in a group mentality with no room for individual differences’ (p. 27); finally, the fifth claim is that solidarity is a typical European value (not to say, continental European value), a kind of “outlandish concept that refers to a Polish trade union or a socialist ideology’ (p. 71) and that it cannot and should not be “exported” elsewhere.

Because Ruud ter Meulen is intimately familiar with both conceptions of justice and of solidarity and moves freely between them, he contributes to our thinking on them with an in-depth analysis. Answering to these five claims, he elaborates innovative and enlightening views on the two questions mentioned above.

In the first chapter, Ruud ter Meulen focuses on the “origins of solidarity as a sociological concept” (p. 30). He shows how the idea has been elaborated from the end of the 18th century up to the beginning of the 20th century, emerging first as an answer to the challenges raised by the industrialisation of France in the 19th century. In France, the weight of normative sociology, especially embodied by Durkheim, and strongly criticized by Max Weber, is prevalent. This is an important point as, in this chapter, Ruud ter Meulen

invites the reader to firmly distinguish solidarity and its various motivations (enlightened self-interest, mutual affection and identification, acceptance of moral authority, reciprocity, moral responsibility) as *descriptive* categories from their moral meaning. He himself considers that the philosophy of solidarity has an “autonomous status” and “cannot be reduced to empirical findings” (p. 25) or pretend to be grounded on such findings. This is the answer to the first claim mentioned above.

The moral significance of solidarity and its various motivations are considered in the second chapter dealing with solidarity and justice as, so to speak, political competing grammars. Starting with an examination of John Rawls’ theory of justice and its application to health care issues by Norman Daniels, he proposes an analysis of their criticism from various angles, particularly the capability approach, the conception of a decent society and the relational vision of solidarity consistent with the recognition of individual differences. This leads him to propose a view combining solidarity and justice: in order to escape the ‘cold side’ (p. 84) of the latter, it appears necessary to design health care policies founded both on justice and solidarity: “the concept of solidarity tries to capture the commitment to the well-being of the other by emphasising the importance of recognition of identities and the promotion of dignity in the context of personal relationships. This is not to say that justice should be discarded in the arrangement of health care policies and practices in favour of solidarity: solidarity does not attempt to offer an alternative for distributive justice, but must be regarded as an important corrective to arrangements of health care practices that are based on a just distribution of goods only. Health care policies and arrangements should go beyond merely meeting needs and rights, by exploring how personal dignity and sense of belonging can be sustained within relations of recognition, reciprocity and support” (p. 107).

This important normative proposal, which is an answer to the second, third and fourth claims, is not the only result of the second chapter. Ruud ter Meulen has also built a useful distinction through his analysis of the theory of justice and of its criticism: between solidarity as a general attitude among the population and a basis for welfare arrangements, and solidarity as a set of concrete practices of care for the needs of others. Taking the Dutch health care system as a case-study and a broader international set of data about informal care giving and family care, the following two chapters offer a concrete and detailed analysis of both types of solidarity. They also examine the shifting balance between collective responsibility based on the principle of solidarity, and individual responsibility and financial contribution to health and social care service. Both orientations have certainly their respective pitfalls and advantages. However, the position of vulnerable

people, whether because of health condition, social isolation, or economic frailty, remains to be fully addressed in a context of shifting policies toward increased individual responsibility. Informal care giving or family care get a prominent role in this context. Their examination allows Ruud ter Meulen first to demonstrate why there should be a collectively organised support of this type of care. With such a perspective, he completes his answer to the claim about the contemporary role of the state in organising a health care system based on solidarity. Besides, in this chapter, referring to the conception of reflective solidarity such as advocated by Jody Dean, he clearly shows how solidarity is not contrary to the recognition of individual opinions, preferences and values (p. 163).

The sixth chapter presents the main conclusions of the book – coming back on the various claims discussed in it and on the answers proposed by the author. It does also propose theoretical, sociological and historical elements to question the fifth claim about solidarity as “an exclusive European value” (p. 178). They convincingly bring the reader to consider this claim more as a prejudice than as a grounded idea.

Overall, the conceptual and normative stance of Ruud ter Meulen should not seem too excessive, even to the fiercest opponents to solidarity: it mainly advocates for solidarity as “a corrective force” and not as a replacement for justice (p. 186), in order to make sure that our societies commit “to sustain the life of fellow human beings, particularly when their conditions are becoming difficult to bear” (p. 186).

The elaboration of this stance throughout the book is quite astute. Ruud ter Meulen's line of argument is designed to make it very convincing. As a matter of fact, his initial contextualising work on the concept of solidarity shows that it has an international history from the very beginning and thus paves the way to his answer to the fifth claim. Besides, his discussion of the theory of justice is partly based on conceptions that have not fundamentally questioned this theory, but rather, tried to improve or complete it. His long-time reflection on the notion of solidarity has also allowed him to have a clear view of the limits of communitarianism and to opt for a conception of solidarity consistent with the recognition of individual differences. Another striking aspect of his argument is that he does not discuss the economic constraints argument used by the advocates of health care systems based in individual responsibility; he rather seems to accept it, just mentioning the “breaking point” situations it may lead to (p. 166). Finally, he offers a brilliant philosophical lesson that is also useful for his ultimate purpose: contextualising the concept of solidarity as he does, he enables us to see it as an answer to concrete issues and not as an ossified idea, inappropriate to deal with contemporary health care challenges.

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BOOK REVIEW - Marie-Hélène Boucand « Une approche éthique des maladies rares génétiques Enjeux de reconnaissance et de compétence »

Elle-même atteinte d'une maladie rare, Marie-Hélène Boucand a été chef de service aux Hospices civils de Lyon (réadaptation). Son livre traite les multiples dimensions des soins aux personnes atteintes d'une des quelque 7000 maladies rares génétiques connues – et le statut de ces maladies.

Contacts avec le système de soins. « Les retards diagnostiques, la banalisation des symptômes, les jugements formulés suscitent un rapport conflictuel initial avec le corps médical. Période d'errance et de galère. » « La posture du médecin face aux maladies rares plaide pour une médecine de l'incertitude où il devient possible de dire 'Je ne sais pas, vos symptômes ne m'évoquent rien de connu, je vais demander un avis spécialisé' »

L'annonce diagnostique : « Après la dénomination de la maladie, le premier sentiment est souvent celui du soulagement. Le diagnostic permet de comprendre le pourquoi de symptômes qui semblaient venir de nulle part. » Mais ce n'est pas toujours le cas. A plusieurs reprises est évoquée une épée de Damoclès. « La transmission est souvent associée à une forte culpabilité de la mère - fantasme de transmission (...) la transmission devient objet de décision alors qu'elle n'est que le fruit du hasard et ne nous appartient pas. » « La maladie rare génétique illustre une modernité de la contagion. Elle prend le sens métaphorique de la transmission à un proche (...) Le gène de la science contemporaine vient remplacer le microbe pasteurien. »

« L'enjeu de la reconnaissance est un point fort du vécu ; il va, paradoxalement, en émerger une grande force de solidarité (...) Le soin devient alors partagé, tant prodigué par les soignants que par le malade qui, apprenant à prendre soin de lui, peut prendre soin des autres. »

Patients-experts, - partenaires, - formateurs. Un chapitre leur est judicieusement consacré. « Quel chemin parcouru entre la posture paternaliste où le médecin savait ce qui était bon pour 'son' patient sans lui délivrer aucune information, et la conversion marquée par la loi Kouchner de 2002. » « Les nouvelles

figures de patients, instaurées par les malades du sida et confirmées par ceux touchés par une maladie chronique et/ou rare, c'est la capacité de prendre la parole et de décider. » Les patients-formateurs sont apparus, dans la foulée des travaux sur l'éducation thérapeutique de J.-Ph. Assal et A. Lacroix, à Genève. Noter que cette compétence fait l'objet depuis 2010 d'une reconnaissance officielle universitaire (DU).

Une médecine de l'adaptabilité. « La médecine ainsi envisagée est celle d'un accompagnement dans le temps pour apprendre comment faire face et résister à l'abatement. Il s'agit d'adaptabilité au sens de Canguilhem, capacité de la personne à retrouver en elle un équilibre au long cours, avec ses nouvelles capacités et limites. Une médecine qui accepte l'échec, lorsque plus rien ne peut être tenté pour guérir. « A 60 ans, handicapé, j'ai une bonne qualité de vie. Je ne suis plus impatient de guérir. »

De larges passages sont consacrés à d'autres aspects : le vécu social et familial de ces patients, le « regard des autres », pas toujours aimable ; le soutien social en ligne par réseaux et forums ; l'utilité des associations de patients (ou de proches). Un chapitre traite de la méthode narrative et de la reconstruction identitaire.

Cet ouvrage est une somme sur les maladies rares génétiques, y compris au plan épistémologique et sociologique. Très bien informé, bien écrit, il apporte une importante contribution, selon la préfacière, « pour avancer sans complaisance dans l'exploration philosophique et humaine d'un monde multiple, mal décrit et mal perçu. »

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REFUSING TO LIVE WITH DEMENTIA

La dernière livraison du *Hastings Center Report (HCR)* comprend un article principal de Norman Cantor, professeur de droit de l'université Rutgers, « On avoiding deep dementia » (1). Il est un militant du droit de mettre un terme à ses jours (autonomie). « Certains entendent faire face à la maladie d'Alzheimer avec une certaine résignation [mais aussi] la détermination de se battre, en extrayant les comforts que l'existence peut encore apporter. Pour d'autres dont je suis, le fait d'être maintenu en vie alors que je présenterai une dysfonction cognitive et une dépendance progressives est une perspective intolérablement dégradante (...) J'accorde une très grande importance aux souvenirs posthumes que je laisserai et souhaite que ma trajectoire de vie soit cohérente avec ma vision de la dignité. » Problématique connue, bien posée.

Cantor débat en détail du rôle possible de directives anticipées (DA – *Advance directives*), en particulier de DA qui mandatent l'arrêt de l'hydratation et de l'alimentation quand un stade prescrit de maladie est atteint. S'agissant de ce stade, il propose (pour lui) « une dégradation mentale au point où je ne pourrais plus lire et comprendre des écrits tels que journaux ou documents financiers ».

« Quand la démence entraîne l'incapacité mentale et physique de se nourrir, alors l'alimentation (*hand feeding*) par un soignant doit être vue comme une intervention médicale sujette à DA », écrit-il. Dans le cas de personnes en fin de vie (cancers, maladies neurodégénératives), l'opinion éthique prévalente est que le malade peut requérir une telle cessation (*voluntary stopping eating and drinking – VSED*) et que le forcer à s'hydrater ou manger est une violence, pas admissible. Et, dans ces situations, l'avis majoritaire est que les personnes ne souffrent pas de soif ni de faim. La difficulté sérieuse dans le cas de la démence est que la forme physique de ces patients peut être encore assez bonne ; ils ne vont donc pas s'éteindre à brève échéance. D'où la perspective de fins de vie prolongées, voire agitées, s'ils ne sont plus ni alimentés ni hydratés. Même si la détermination affirmée de la personne de mourir est en soi jugée compréhensible, les soignants et proches seront mis dans des situations très difficiles. Il y a là clairement un problème.

L'article de Cantor est suivi de trois répliques sous le titre « Other voices ». Les trois sont opposées à son souhait, avec l'argument que l'individu ne peut pas par ses DA obliger les soignants à le traiter de manière « inhumaine ». Avec aussi, sous la plume de Rebecca Dresser, juriste universitaire collaborant souvent à la revue : « Certaines situations peuvent à tel moment justifier la décision de refuser tout traitement. Mais on ne saurait donner aux personnes, par des DA rédigées alors qu'elles sont capables de discernement, un contrôle absolu sur les mesures visant à les maintenir en vie quand elles seront(-aient) devenues démentes ». Position de tendance paternaliste-conservatrice, avec laquelle on peut être en désaccord respectueux - quant au principe.

Sur un autre thème : le même numéro du *HCR* inclut un article remarquablement différencié et pondéré, par un enseignant de pédiatrie, sur les manières de répondre à des demandes de patients ou de proches en rapport avec certaines caractéristiques des soignants, notamment le genre ou la couleur de peau (2).

1. Cantor N.L. On avoiding deep dementia. *Hastings Center Report* 2018, vol. 48, no. 4 (July-August), 15-24.
2. Rosoff Ph. M. Discriminatory demands by patients – même référence, pages 7-11.

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