

EACME Newsletter

European Association of Centres of Medical Ethics

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EDITORIAL

A farewell, an acknowledgment, a wish

I'm writing this editorial while I am high up in the mountains, in front of a nice partially ice covered crown of peaks, and with a wide green valley which opens beneath. From so high up, my attention and thoughts are roaming freely, with lightness, peace and hope.

FAREWELL

Primarily, I would like to send my warm farewell salutations to all Members, at the end of my mandate as EACME President. It was a fine experience lived in collaboration and a spirit of service for our Association; we faced a phase of changes and new challenges, which we incurred after twenty five years of life. The situation of the recent yearly Conferences in Oslo, Istanbul, Bristol and now Bochum, have given us a sense of vitality and movement throughout Europe, varying the nature of themes expressed (Empirical Ethics, Bioethics from a cross-cultural Perspective, Other Voices-Other Rooms, Personalised medicine-Medicine for the person?).

ACKNOWLEDGMENT

A thank you to all the Centres which hosted our Meetings, and also a thank you to all the Centres that form EACME, as an association which valorises Institutions/Centres where, of course, there are motivated people who are devoted to the Bioethics themes and who share the ethos of EACME. But my personal thanks is for the Bureau/Executive Committee colleagues, Rouven Porz and Chris Gastmans, a warm thanks for the precious and efficient Angelique Heijnen (Executive Office) for the peaceful and successful work done together. And thanks to the Board of Directors, to the past Presidents and to all the Members with whom we shared these years and with whom we will keep on sharing EACME life.

I am getting busier and busier in Rome, at the Pontifical Academy for Life, and partially in Padova at the Lanza Foundation. But I will always try to share the mission and the features of the Association. An association lives, after the first initial enthusiasm, for the confidence, the diligence and for the active contribution of all its Members, keeping up the exchange of experiences, perspectives, diversity of inspiration and philosophical-religious opinions, without preconception or fear, without jealousy or search for personal prestige. After twenty five years since the birth of EACME, a lot things have changed, including: new geographical and political European scenery, the development of a certain Bioethics "institutionalization", the increase of European and national rules/laws in the Bio-medicine field, the succession of people who created the Association. Several "Founding Fathers", who we remember with gratitude are now retired and some have sadly passed away. Particularly, in these recent years a severe economic crisis has limited financial and human resources, and has also involved the health care world, academic institutions, and others; in this way certain differences are increasing within the European Union. In this scenario, with bright and dark, I believe EACME could draw again on its initial inspiration and in light of the recent "Mission Statement EACME" could pursue a successful route, helping younger generations, young researchers to cultivate a keen collaborative spirit in the Bioethical field.

WISH

My wish is that we extend ourselves, in particular for the new Bureau, to face bravely and with creativity the new challenges, that is with the impulse and the style which characterized the beginning of Bioethics. Recalling the sharp and stirring considerations made by Paul Schotsmans (see EACME Newsletter September 2012), I allow myself to mention only some challenges I think are important:

- The multicultural and multireligious scene which is developing in Europe, which needs to deepen languages, concepts, and methodology for an authentic dialogue which leads us to interact between the universal and the particular in the Ethics and Bioethics field; and to interpret the contribution from various cultures and religions to bioethical issues
- The relation between "general Bioethics" and "specialized Bioethics", that is between ethicists devoted to reflections about fundamental aspects and other different themes and ethicists specialized in a well defined field obtaining, aside from ethics competence, the scientific and legal ones involved; this is positive, but it risks fragmentation and the development of various "sectional bioethics" with a difficult dialogue among them.
- The continuous contact with real clinical life, the effective problems in the clinical setting, lived by

doctors, nurses, and other health care professionals. This avoids Bioethics becoming "abstract", "to indulge in virtuosity", and not very useful for healthcare operators, who are, on the other hand, more and more stressed by economic pressures and by organizational difficulties, so that they feel that many bioethical reflections are distant from the real situations they usually live. Therefore a fundamental role is carried out by Clinical Bioethics.

- So, with regard to a more and more technological medicine, standardized, and as others remember, with always more and more depersonalization, there is a growing need to focus on people, on their experience of suffering and hope and a concrete "Care" for them. Paraphrasing the famous article written by S. Toulmin in 1982, "How medicine saved the life of ethics", today we might say "How ethics could save the life of medicine".
- On the other hand, there's by now the risk that Bioethics becomes just another academic subject among the others, losing the characteristic of a "bridge" between the different fields of knowledge and action, and between the academic- scientific world and the Society, raising always a "prophetic", critical and stimulating voice towards medicine and the society itself.
- The attention towards the weakest, the most vulnerable people, and the passion for justice, for rightful healthcare systems able to answer each generation and incoming health necessities of "new poor people", has been a continuous challenge to Bioethics.

I allow myself to remember Papa Francesco's concern who made the first trip to Lampedusa island, recalling the new scenarios which have developed due to immigration and the necessity to protect the human rights of many suffering people, and he has begun to overcome the "globalization of indifference". Thus the new social phenomena, the severe problem of environmental crisis, the globalization of information and the economic dynamics, exhort us to elaborate conceptual instruments and guidelines of an ethics which considers these broad and complex phenomena. As people involved in Bioethics, as bioethicists, we wish to bring our small but precious contribution which, strengthened by our collaboration in the Association, can become a concrete "bridge to the future", a real "ethics for life", for everybody.

The sun is rising among the mountain tops, a wonderful event that takes place every day: and hope is warming, and is flying towards the infinite horizon....

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PRESENTATION OF THE EACME 2013 HOST – THE INSTITUTE FOR MEDICAL ETHICS AND HISTORY OF MEDICINE, RUHR UNIVERSITY BOCHUM

In view of the upcoming EACME conference 2013 in Bochum, we would like to present you its host - the Institute for Medical Ethics and History of Medicine, Ruhr University Bochum (Director: Prof. Dr. Dr. Jochen Vollmann).

Bochum, a city formerly determined by coal mining and the steel industry, is today an urban centre for services and education – with the Ruhr University Bochum as one of the ten biggest universities in Germany. The Institute is situated in a coal-mining shaft tower, outside the campus of the Ruhr University Bochum, which was reconstructed as a monument and museum. The historical building hosts an exhibition on the historical foundations of medical technology as well as medical aspects of the former mining activities in the Ruhr area.

The academic work of the institute is interdisciplinary, involving medical ethicists, philosophers, physicians, sociologists, lawyers and scholars from other disciplines in its working groups. Main research areas of the institute are ethical issues in clinical practice and medical research (e.g. mental health, end-of-life decisions, informed consent, doctor-patient communication) as well as methodological aspects of medical ethics (e.g. empirical medical ethics). For its' innovative undergraduate and postgraduate education the institute received several teaching awards.

Since 2011, Prof. Vollmann coordinates the BMBF-Collaborative Research Project "Personalised medicine in oncology – ethical, medical, health economical and legal aspects" which is funded by the Federal Ministry of Education and Research and which will be represented at the EACME conference 2013. The institute has established interdisciplinary research collaborations on a national and international level. In order to support junior researchers, the institute engages in special programmes such as the International Visiting Fellowship Programme, which enables international scholars to work at the institute. In addition, research seminars, lunchtime meetings and public lecture support interdisciplinary discussion, international collaborations and community outreach in the field of medical ethics.

The EACME conference 2013 will take place on the main campus of the Ruhr University Bochum and is organised in cooperation with the interdisciplinary Centre for Medical Ethics Bochum (Zentrum für Medizinische Ethik Bochum). The centre was founded in 1986 as the first interdisciplinary academic institution of medical ethics in Germany. It specializes in developing

practical instruments for moral assessments in biomedical research and patient care, and in specialized consultation and ethics training of health care professionals. The EACME 2013 will be supported by the Research Ethics Committee of the Medical Faculty, Ruhr University Bochum.

As the centre of the Ruhr Metropolitan Area and as part of the European Capital of Culture in 2010, Bochum is well-known for its modern culture and industrial heritage. If you wish to relax from the conference or to develop your thoughts in a beautiful and thought-enriching surrounding, a visit to the botanical garden, located next to the conference centre, is highly recommended.

We are looking forward welcoming you on the EACME conference in Bochum. Have a safe trip and enjoy a stimulating conference, interesting discussions and a pleasant conference dinner.

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THE 9TH INTERNATIONAL CONFERENCE ON CLINICAL ETHICS CONSULTATION HELD IN MUNICH, GERMANY

A few months ago, 200 colleagues gathered in Munich, Southern Germany, for the 9th International Conference on Clinical Ethics Consultation (March 14-16, 2013). This conference series was launched ten years ago by the transatlantic team of George Agich (then at Cleveland) and Stella Reiter-Theil (Basel) to offer a global platform for the scientific exchange in clinical ethics. Since 2007 the conference has been held annually on alternating continents and has already been in North and South America, Europe, and Asia.

This year's conference was entitled "Clinical Ethics: Bridging Clinical Medicine and Ethics" and wanted to reach out to health care professionals, thus strengthening the bridge between ethics consultants, ethics researchers, and clinicians. In line with this motto of the bridge the congress was organized by a physician, the oncologist Wolfgang Hiddemann, aided by two clinical bioethicists, Eva Winkler and Ralf Jox, and took place in the Munich University Hospital. The idea of the bridge was also built into the program: the plenary sessions were structured in a way that a health care professional expressed clinical needs regarding an ethically relevant topic and an ethicist responded

considering what clinical ethics consultation can contribute to meeting these needs. Along this structure the plenary sessions covered the roles of clinical ethics consultation in general treatment decision making, intensive care, dementia care, oncology, and transplantation medicine. The slides of all plenary presentations are accessible at the conference website (www.iccec2013.de). In focused panel sessions, clinicians and ethicists discussed the contribution of ethics consultation to genetic counselling for inheritable disorders and to prenatal and perinatal care.

It was generally apparent that ethics consultation is in a stage of discovering neglected areas beyond the classic ones of intensive care medicine, cancer care and gynaecology/neonatology. In one parallel session, colleagues reported first experiences of ethics consultation in psychiatry, another session highlighted special consideration in paediatrics, and still another one explored applying ethics consultation to the care of minority groups, such as native populations, immigrants or prisoners. A high number of oral presentations focused on the concepts of quality, competence, accountability, and evaluation of ethics consultation. This is emerging as a pressing question in many countries, and the range of answers spanned from philosophical reflections to very specific instruments to measure or improve quality.

As the number of submitted abstracts was unexpectedly high, the conference also highlighted two poster sessions, offering about 70 authors the chance to discuss the research, ideas and experiences in a more informal way. A novel element of the program that was particularly popular was called "ethics consultation in practice". In three different sessions, experienced ethics consultants were demonstrating their own method of doing case consultations. Real and current cases were presented by clinicians from the Munich area, each of them followed by a roundtable discussion with several professionals involved in that case and the ethics consultant as moderator. Stella Reiter-Theil (Basel), Paul Ford (Cleveland) and Georg Marckmann (Munich) as ethics consultants displayed a wide variety of approaches. In the ensuing discussions with the audience, it was debated whether case consultations should be more structured or flexible, directive or non-directive, normative or pragmatic.

Among the 200 attendees of the conference, most came from Western Europe or North America, but there was also a considerable number coming from Eastern European countries and some colleagues even travelled from Asia and South America. It may be the challenge for a future conference to explore ways of ethics consultation on the African continent. This

year's conference also took the chance to distinguish excellence in clinical ethics consultation. On the basis of their excellent abstracts, Elisabeth Gjerberg (Oslo), Richard Huxtable (Bristol) and Valentin Schnurrer (Basel) were selected for the best paper session. On the conference dinner and social evening in the historic hall of the *Lenbach Artist House* in the heart of Munich, the first prize in clinical ethics was celebrated: Hugo Gold, Lynn Gillam and Catherine Lees (Melbourne) received the *Hans Joachim Schwager Award*, named after a pioneer in clinical ethics from Germany. The team at the Royal Children's Hospital in Melbourne, Australia, were distinguished for the fast development of an exemplary consultation service with a rapid response group, efforts in quality management and activities to enhance public understanding.

This award has just been announced for the second time (see: www.clinical-ethics.org) and it will be given at next year's conference of this series which is to be held in Paris, France, on April 24-26, 2014. The motto will be "The Patient's Voice" and abstracts can be submitted until September 20, 2013: www.iccec2014.fr

Looking back at the Munich conference, I want to take the opportunity to thank all who contributed to the success of this meeting: the steering team of the conference series George Agich and Stella Reiter-Theil, the many members of the Scientific Committee and the clinicians in the Advisory Committee, the German Research Foundation, Celegene GmbH and Roche Pharma AG for financial contributions. The greatest credit, however, must be given to the local organizing team, the chairman Wolfgang Hiddemann and Eva Winkler, who joint me as scientific secretary, Alexandra Schydlik and Beate Buske-Kosel for the huge administrative work they did, Friederike Mumm, Pia Heußner and Georg Marckmann as well as the many students and workers for their support. But most importantly, we have to thank all colleagues who participated in the conference and engaged in a fascinating and fruitful exchange of ideas, insights and experiences. We hope to see all of them - and all of you - next year in Paris!

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BETWEEN PATIENT AUTONOMY AND PHYSICIANS' RESPONSIBILITY TO SAVE LIFE: THE IMPLEMENTATION OF ADVANCE DIRECTIVES IN THREE EUROPEAN COUNTRIES (ENGLAND, FRANCE AND GERMANY)

Respect for patient autonomy is an essential part of modern medical ethics in Western countries (Beauchamp, Childress, 2008). It follows that situations in which a patient is unable to communicate her will generate an ethical problem. For the past few years, advance directives (ADs) have been discussed as one possibility to resolve this problem. ADs aim to enable a person to exercise her autonomy even while she is incompetent by recording in advance her decisions relating to treatment refusal. Several countries, such as France, England and Germany already accorded legal value to these devices and the Council of Europe (2009; 2012) recommended recently that all member states should adopt legislation on these issues. Yet, the legitimacy of anticipated treatment refusals raises difficult ethical, legal and social questions. Further, different countries treat ADs with varying degrees of importance. Some countries understand them as legally binding while others think they may be overruled. My work examines the socio-political and cultural contexts giving rise to differences in the ways different countries treat advance directives.

An EU funded Marie Curie Fellowship at the Centre for Ethics in Medicine in Bristol provided me with the opportunity to investigate the socio-political and cultural contexts of England and France. After comparing these country's legislation, arguments employed in public discourses (parliamentary reports, reports of National Ethics Committees, professional guidelines), and physicians' attitudes (14 interviews/country), I found that ADs raise different ethical considerations in these two countries (Horn, 2012). In England, arguments focus on difficulties in identifying a person's authentic autonomous will, but in France the debate focuses on the risk that obliging physicians to respect ADs may cause physicians to lose their sense of responsibility for and solidarity with the vulnerable person. The concerns that exist in each country regarding ADs raise doubts about whether these devices will ever be applicable in practice.

This research generated useful information about the role of patient preferences in medical decision-making processes in general, and more particularly about the (potential) role of ADs in England and France. Yet, I found that further research is needed in order to verify the hypotheses which have emerged. My research to date has relied on interviews with professionals outside

of the clinical context in which problems related to ADs arise. I plan to extend this work and to increase knowledge about the practices and problems actually encountered in the decision-making processes for incompetent patients by exploring, through ethnographic fieldwork, current practices and ethical problems that emerge in physicians' daily practices. This investigation aims to explore whether ADs matter in practice and, if yes, to uncover the factors, in addition to patient preferences that come into play when making end-of-life decisions for incompetent patients.

Having secured funding from the Wellcome Trust I am currently pursuing comparative sociological research that aims to increase the understanding of the practical use of ADs and the reasons healthcare professionals or patients have to employ or not to employ this instrument. This research is carried out at The Ethox Centre in Oxford.

This research aims to increase knowledge about ADs by including an examination of a third country, Germany, which employs a different approach to ADs than France or England. The debate and professional recommendations in Germany suggest an emphasis on the importance of integrating the patient or her family in the decision-making process. This is common to both Germany and England while the power of decision-making in France resides primarily with the doctor (De Vries et al. 2009; Horn, 2013). But in spite of this similarity between Germany and England, the importance placed on patient autonomy in each of these countries is motivated by different principles. In England, the importance of patient autonomy is founded on the concept of liberal autonomy (Münch, 1986) while in Germany, the Kantian principle of responsible autonomy, in a Kantian sense (Krones, 2006; Horn, 2013).

My research programme over the next three years seeks to (1) identify, through discourse analysis, the principal actors, their arguments and the influence they exert on the formulation of questions regarding ADs, (2) explore, through ethnographic fieldwork, involving direct observations (4 months in each country) and semi-directive interviews (20 in each country) the ethical landscape and concrete problems doctors face regarding decisions to discontinue treatment and regarding the use of ADs, and (3) highlight particularities in each country by comparing discourses and practices.

This research aims to contribute to a better understanding of the ethical problems generated by the implementation of ADs in daily end-of-life practices, and regulatory and practical solutions adopted by each country in order to manage these problems. Finally, this project aims to generate a more nuanced and

informed ethical analysis and policy making regarding the use of advance directives in each of the three countries but also in Europe (and beyond).

My research is in its early stages. Review of the literature has been started and I am currently applying for institutional ethical review in the three countries, with plans to begin fieldwork in autumn 2013, with analysis and publishing results continuing until early 2016.

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ETHICS OF PRENATAL SCREENING: BRIEF REPORT OF A SUCCESSFUL SYMPOSIUM

At the shores of lake Geneva, in the well-facilitated conference building of the Brocher Foundation, a 1,5 day symposium was held on the ethics of new developments in prenatal screening (4-5 April 2013).

This concerned several scenarios in which non-invasive prenatal testing (NIPT) may replace different parts (or eventually the whole) of the present screening trajectory for fetal aneuploidies, as well as the clear tendency to broaden the scope of (follow-up) testing by using micro-arrays, eventually perhaps to be superseded by whole exome or genome sequencing based testing. These developments and scenarios raise important questions regarding the normative (ethical, legal) framework for screening for fetal anomalies. For instance: in response to the so called 'disability rights critique' (maintaining that the offer of prenatal testing for conditions such as Down syndrome reflects a discriminatory attitude towards people with mental disabilities), it has often been stressed in official documents and statements that such testing should not be understood as aimed at preventing as many children with Down syndrome as possible, but rather as promoting the reproductive autonomy of individual couples.

Taken seriously, this means that the introduction of a new test should not just be evaluated in terms of its better test characteristics, but also in terms how it would affect this aim. In this connection, one concern that has been raised about the prospect of NIPT as allowing 'early, easy and safe' aneuploidy testing, is that it might lead to a 'routinisation' that would be ill at ease with promoting autonomous decision making by pregnant women and their partners.

Moreover, scenarios of (considerably) broadening the scope of testing raise questions about the feasibility of meaningful informed decision making: would offering an extended range of choices serve or undermine reproductive autonomy? If the notion of 'maximizing' autonomous choice is inherently problematic, because it would lead to information overload and less well-considered choices, it seems that the classical aim of prenatal screening requires qualification.

If, inevitably, the question arises for what conditions prenatal testing should be offered, then who should decide about this and on the basis of what criteria?

These are only some of the issues that emerged at the well-attended symposium. The meeting was organized by researchers at the *Health, Ethics & Society* department of Maastricht University, the Netherlands, as part of the PhD project of Antina de Jong (supervisors: Guido de Wert and Wybo Dondorp,

Bioethics, Maastricht, and Jan van Lith, Gynaecology, Leiden).

Invited speakers were Lyn Chitty (Genetics and Fetal Medicine, UK), Idit Maya (Clinical Genetics, Israel), Martina Cornel (Community Genetics, the Netherlands), Jenny Hewison (Psychology of Health Care, UK), Christian Munthe (Practical Philosophy, Sweden), Stephen Wilkinson (Bioethics, UK), Antina de Jong MA, LLM (Bioethics, the Netherlands).

The meeting was attended by a further thirty interested professionals from a broad range of disciplines and a large number of countries, including Argentina and the USA. The general feeling was that the symposium timely addressed important questions and that ideally this meeting should not be a one off event but the starting point of a longer term multidisciplinary endeavor, perhaps in the form of a Special Interest Group of ISPD. Planned publications based on the meeting include a paper to be submitted to *Prenatal Diagnosis* and a special issue of *Bioethics*.

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IN MEMORIAM: DR RON BERGHMANS

17 November 1954 - 16 March 2013
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What had become inevitable nevertheless hit hard, when our colleague Ron Berghmans passed away on March 16. The cancer he had previously battled returned in late 2012, this time with a vengeance. It soon became apparent that it was an unequal struggle. Though he fought bravely, after many setbacks he lost the fight.

Trained as a psychologist, Ron first worked in Utrecht as a patient advocate at the Stichting PVP, a foundation for the protection of clients' rights in the mental healthcare sector. His experiences in mental health care provided a good background when, in 1986, he took up a PhD position at the former Institute for Bioethics (IGE) in Maastricht. Supervised by Professor Harry Kuitert in Amsterdam, he focused his research on the ethics of paternalism in psychiatry. Showing great dedication and analytical skill, he produced a seminal dissertation that would direct the debates in the Netherlands on the tension between doing good and respecting the autonomy of psychiatric patients for years to come. His ability to look beyond the borders of his discipline was evident from the high

esteem in which he was held by health lawyers on issues such as the role of living wills.

Ron was one of the first Dutch ethicists to publish widely in English, which meant his voice came to be heard – and respected – abroad as well. Meanwhile, his academic horizons expanded to include the debate on euthanasia and the ethics of medical research involving human subjects. It was no surprise when the Health Council of the Netherlands sought his advice; his expertise was beyond dispute. This was also clear at the IGE, of which the growing reputation was largely to be attributed to Ron.

When the IGE became part of Maastricht University, Ron devoted his energies to education also. He enjoyed the interactive teaching method used in Maastricht, with its small groups of students. They, in turn, highly valued his patient-centred ethic.

Ron worked hard, but as he knew, life is about more than just work. Naturally, he treasured his holidays with his wife and children. Ron had pledged his heart to Venice. Critical as he was of coercion in healthcare, he nevertheless emphasized that everyone should be forced to visit Venice at least once, 'for their own good'. Ron visited several EACME conferences. When in 2001 he was present in Padua together with former EACME Newsletter editor Rob van Hooren and Angelique Heijnen he, of course, took this opportunity to visit Venice and to guide them both around.

Even in the last period of his illness, Ron continued writing. Given his accuracy and fine argumentation, it was a pleasure to write with him. One of his last papers was "Physician-assisted suicide in psychiatry and loss of hope". It was published last July, posthumous, in the International Journal of Law and Psychiatry. Please find below the summary of this paper.

We have lost a fine ethicist, a great colleague and a dear friend.

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Article: Physician-assisted suicide in psychiatry and loss of hope.

Ron Berghmans, Guy Widdershoven, Ineke Widdershoven-Heerding

ABSTRACT: In the Netherlands, euthanasia and physician-assisted suicide (PAS) are considered acceptable medical practices in specific circumstances. The majority of cases of euthanasia and PAS involve patients suffering from cancer. However, in 1994 the Dutch Supreme Court in the so-called Chabot-case ruled that "the seriousness of the suffering of the patient does not depend on the cause of the suffering", thereby rejecting a distinction between physical (or somatic) and mental suffering. This opened the way for further debate about the acceptability of PAS in cases of serious and refractory mental illness. An important objection against offering PAS to mentally ill patients is that this might reinforce loss of hope, and demoralization. Based on an analysis of a reported case, this argument is evaluated. It is argued that offering PAS to a patient with a mental illness who suffers unbearably, enduringly and without prospect of relief does not necessarily imply taking away hope and can be ethically acceptable.

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For further information, see his blogspot:
<http://rberghmans.blogspot.com/>

SOINS PALLIATIFS – TOUJOURS DIFFICILE D'ÊTRE PIONNIER

Les soins palliatifs, aujourd'hui promus activement par l'OMS, font l'objet en Suisse d'une stratégie nationale (dans d'autres pays aussi) et de programmes cantonaux. Sujet très important dans une société où moins de 20% des personnes ont la chance de mourir à domicile alors que, avec un niveau adéquat de tels soins, ce pourrait être 80%. Pourtant, le nécessaire changement de paradigme et de mentalité se fait très lentement. « L'acharnement thérapeutique en fin de vie est toujours fréquent, ce qui représente un

problème autant éthique que pratique », dit le professeur G.B. Borasio, aujourd'hui à Lausanne après avoir été très engagé dans ce domaine à Munich.

En France, le prof. Didier Sicard, ancien président du Comité national d'éthique, a dirigé une commission qui a publié à fin 2012 un rapport sur la fin de vie (1). Ses conclusions peuvent être dites dévastatrices : « Nos auditions ont mis au jour le malaise, voire la colère des citoyens ; de nombreuses situations de fin de vie ne sont pas correctement appréhendées (...) La recommandation première est de donner la plus grande importance aux paroles et aux souhaits des malades en fin de vie ». En effet, malgré les changements entérinés quant au principe, par la loi Leonetti de 2005 notamment, le corps médical traîne massivement les pieds pour adopter des pratiques qui amélioreraient clairement la qualité de la vie dans sa dernière phase – tout en la *prolongeant de plusieurs mois* par rapport à l'acharnement, dans des études randomisées. Aux Etats-Unis, pourtant très sensibles à l'autonomie du malade, les médecins continuent souvent à refuser de dire au patient que le pronostic est mauvais et qu'il va mourir.

A cet égard, l'autobiographie (2) de Elisabeth Kübler-Ross (1926-2004), d'origine suisse, mondialement connue pour s'être battue avec courage et persévérance pour une approche de la mort plus ouverte et plus humaine, est très intéressante : histoire d'une jeune femme (une de trois triplées !) dans une famille de Zurich, avec ce que cela représente de sérieux et de travail. Qui s'engage comme volontaire à la fin de la Deuxième Guerre mondiale dans des régions dévastées (France, Pologne), fait un apprentissage de laborantine puis devient médecin. Emigre aux Etats-Unis, devient psychiatre un peu par hasard et pratique son métier en mettant un accent déterminant sur le contact, l'écoute, l'empathie. Elle travaille avec des mourants et mène avec eux des séminaires à succès – suscitant de la part de confrères des critiques selon quoi elle « exploite » les patients. Elle a marqué par sa description de cinq stades chez la personne en fin de vie : déni, colère, marchandage, dépression, acceptation. S'intéresse ensuite beaucoup aux expériences de mort imminente.

L'émergence du sida au début des années 1980 la trouve prête à travailler avec ces malades irrémédiablement condamnés à l'époque. Entre autres, elle cherche à ouvrir un centre de traitement pour enfants séropositifs en Virginie mais se heurte à l'opposition féroce d'« un voisinage de bon chrétiens » (on finit par mettre le feu à sa maison). Elle surprend en montrant un intérêt actif pour des pratiques qui sortent du cadre médical usuel, notamment le « channeling » où des guides de type médiums établissent une communication entre un humain et une

entité appartenant à une autre dimension. Cela a pu la rendre « suspecte » mais il est certain que cela n'autorise pas à la discréditer ; elle a été une pionnière remarquable. Citations en passant : « Les enfants mourants, plus que les adultes, vous disent exactement ce dont ils ont besoin pour être en paix » ; « Dans les ateliers, les participants parvenaient à se défaire de leur *unfinished business* [un point sur lequel elle insiste], de la colère accumulée, et à apprendre à vivre de manière à être prêts à mourir à n'importe quel âge » ; « Il n'y a pas de problème qui ne soit pas en réalité un cadeau et une opportunité de croissance ».

On sait que la grandeur des pionniers, dans tous les domaines, ne leur est souvent accordée qu'à titre posthume. Dans certaines pages de Kübler-Ross, on pense à Ignaz Semmelweis, rendu fou par le refus de la Vienne médicale du milieu du XIXe siècle d'ouvrir les yeux sur la réalité qu'elle tuait beaucoup de parturientes en passant la fièvre puerpérale de l'une à l'autre. Nous n'en sommes pas là aujourd'hui ; néanmoins, la difficulté persistante de trop de professionnels à « accepter la défaite » et à oeuvrer avec le patient pour que sa fin soit la plus libre de douleur, sereine et riche de relations, est un problème.

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Sicard, D.(2012) et al. *Rapport au Président de la République de la Commission de Réflexion sur la fin de vie en France*, 18 décembre.

Kübler-Ross, E. (1997). *The Wheel of Life – a Memoir of Living and Dying* (ce qui fait écho au titre de son livre le plus fameux (On Death and Dying"de 1969). New York: Touchstone.

INTERNATIONAL VISITING RESEARCHER TO THE DEPARTMENT OF MEDICAL HUMANITIES AT THE VU UNIVERSITY MEDICAL CENTER AMSTERDAM

International visiting researcher
Francisco Ródenas, PhD

In the months of June to August of 2013 I have done a research visit in the Department of Medical Humanities at the VU University Medical Center in Amsterdam, thanks to the opportunity that was offered to me by Prof. Tineke Abma. She accepted my application in August 2012 and introduced me to her colleagues, with the support of Prof. Jacqueline Broerse from the Athena Institute at the VU University. The aim of my visit was to finalize a mutually written book chapter as

well as to develop new insights on differences in approaches to long-term care of chronic patients in the Netherlands and Spain. In this short report I will elaborate on my research and reflect on the benefits of my three months stay at the VU University.

Background:

My name is Francisco Ródenas. I have a PhD in Sociology and I'm a lecturer at the University of Valencia (Spain) at the Faculty of Social Science, where I teach undergraduate and postgraduate courses in the subjects 'Research in Social Welfare Systems' and 'Health and Social Care'. I'm director of the official Master's Degree in 'Social Welfare'. Also, I'm a researcher at the Polibienestar Research Institute, where I have participated in several projects on efficiency and quality of social and healthcare systems, funded by the European Commission under the 6th and 7th Framework Programme or programmes such as Ambient Assisted Living or Progress. I'm currently participating at the European Innovation Partnership for Healthy and Active Ageing, in the group B3 relative to integrated care, and in International networks such as International Long-term care Policy Network (ILPN).

Research centre:

The research centre Polibienestar is a Public Research Institute belonging to the University of Valencia (Spain), a university with over 500 years and with nearly 60,000 students. It is specialized in research, innovation and social technology, technical advice and training in the field of public policies. Its final mission is the improvement of the Wellness and Quality of Life of society. It is composed by an interdisciplinary team with 20 senior and 6 junior researchers with national and European experience from the departments of Preventive Medicine and Public Health; Didactics and School Organisation; Educational Sciences; Personality, Assessment and Psychological Treatment; Applied Economics; Marketing; Labour and Social Security Law; Commercial Law; Social Work and Social Services; Sociology and Social Anthropology, from four Universities in Spain (Valencia, Castilla-León, Murcia and Castellón). Polibienestar has a large network of European contacts due to its active role in European research and policy design. More information can be found at the website: www.polibienestar.org

Own research and aims of visit:

One of my main research topics in Polibienestar is addressed to improve the quality of life of elderly people and chronic patients using ICT devices. For this research, we aim to analyse the usability, points of view, needs and requirements of end-users and patients in order to design and assess easy-use and friendly devices. Also, we want to identify and analyse

ICT solutions that contribute to improve the health, active ageing, social participation and independent living for elderly and chronic patients. We are currently discussing with the Ministry of Health of the Valencian Community, the use of ICT solutions in Palliative Care. Moreover, we aim to promote the consideration of ethical aspects related with the use of ICT systems with these patients. For example, in our research we try to answer questions like 'how e-health affects the quality of life of patients?' and 'does e-health mean a change in the moral obligations?' One of the reasons why I chose to visit the Department of Medical Humanities was its high research experience on patient's participation and ethics in the care process, mainly in palliative care.

The other reason was connected with the 'Sustainable socio-health model' promoted together with my colleague Prof Jorge Garcés (University of Valencia). It consists of a joint reorganisation of health and social systems to provide an answer to the long-term care needs of citizens. Within this topic, we analysed the impact of alternative health systems and health interventions in terms of patients' health benefits, the response to the needs of patients, patients' safety, effectiveness and quality of care. This model is included in the book 'Towards system innovations in health systems: Understanding historical evolution, innovative practices and opportunities for a transition in healthcare' coordinated by Jacqueline Broerse (VU University Amsterdam) and John Grin (University of Amsterdam) published in Routledge. During my visit I was able to review my chapter '*Towards a sustainable welfare and health care system in Spain*' (written together with Prof Jorge Garcés) with them and close the final version. In this topic, in order to promote the integrated care, we use assessment tools of health and social system, and apply methodologies with multidisciplinary teams, such as the case management, to create flexible management structures and develop preventive action protocols connected with screening instruments to risk groups (eg, older patients at risk of hospital readmission).

Different approaches of palliative care

During my visit I was able to share opinions and experiences on these topics with colleagues in the department through meetings, seminars and daily dialogues. In particular, I discussed the different approaches existing in Spain and the Netherlands concerning palliative care and ethical issues associated with quality of life and good death, with researchers who are member of the EACME like Professor G. Widdershoven (University Medical Center Amsterdam, Department of Medical Humanities) and Professor E. Van Leeuwen (Department IQ Healthcare, Medical Ethics section UMC St. Radboud). My impression based on these conversations is that

differences in approaches between our countries are conceptual, legal and practical. For example, the debate regarding the option of 'euthanasia' is unresolved in Spain. Yet, in the Dutch practice to apply this option has been necessary to develop laws and moral and quality standards on dying, and define the balance between them. I hope to formalize cooperation agreements between our centers that will facilitate the joint drafting of papers and other scientific publications, training and teaching activities, or collaborate research projects.

I would like to thank VU University Medical Center Amsterdam, and the colleagues of the several departments and centres, in particularly from the Department of Medical Humanities and the Athena Institute.

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Grant from Ministry of Education, Culture and Sport (Spain), Salvador de Madariaga Program 2012.

THÉRAPEUTE ET CONFIDENTIALITÉ PRIS DANS DES NOEUDS CULTURELS

Il m'arrive comme à d'autres d'émettre des réserves à l'endroit d'un certain impérialisme culturel occidental - manque de compréhension de cadres de référence qui diffèrent du nôtre. Il est clair cependant que certaines pratiques doivent être bannies ; ainsi pour les « crimes d'honneur » qui ont cours dans des régions du Proche-Orient ou plus loin en Asie Leur prévention passe par l'implication attentive des professionnels de santé et d'autres.

J'ai reçu récemment un message d'une psychothérapeute travaillant dans une association recevant beaucoup de migrants : « Hier j'ai vu une patiente qui depuis plusieurs séances parle d'une de ses filles qui a commis une faute culturellement inadmissible, disant que son mari et son fils aîné ont l'intention de la tuer. La mère pense qu'il y a un danger réel puis elle en est moins sûre, puis elle le pense à nouveau. Je suis un peu perdue ». Délicat, toujours, en rapport notamment avec la confidentialité/secret médical.

D'abord, il faut se souvenir que dans les cas urgents où sont mis en danger des biens dignes de protection comme la santé ou la vie, on peut passer outre les dispositions légales telles que le secret professionnel : on sauve ce qui peut l'être d'abord, on se met en règle

avec la lettre de la loi après – en se faisant délier formellement du secret. Ainsi, le thérapeute peut et à mon sens doit informer la/les personne(s) menacée(s) et si nécessaire l'autorité : police, ordre judiciaire.

La possibilité d'annoncer doit être utilisée, à temps. Cidessus, noter un point particulier : c'est la mère qui est angoissée et la thérapeute ne connaît pas la jeune femme. Cette dernière sait-elle qu'elle est menacée ? Il convient de faire en sorte de l'avertir; elle pourrait décider de son propre chef de prendre des mesures, comme de s'éloigner ou se réfugier dans un foyer pour femmes en danger.

Penser au fait que, si des autorités interviennent, la mère « dénonçante » pourrait être punie par l'entourage pour avoir parlé à l'extérieur. Un principe standard, ici et ailleurs, est de toujours rester attentif aux intérêts et risques pour des tiers, autour de la personne « centrale ». On a le droit cas échéant de signaler contre l'avis de la mère (respectivement de la fille) mais, autant que faire se peut, la convaincre d'abord du bien-fondé de le faire. Tout en gardant l'urgence à l'esprit.

Quoi d'autre, simultanément ou préalablement si on a un peu de temps ? Penser aux possibilités de diminuer la tension familiale avant de faire appel à des instances publiques. Trouve-t-on dans le groupe culturel des personnes jouissant d'estime et d'autorité informelle susceptibles d'amener ces hommes à la raison. Il s'agit d'une famille d'origine étrangère: aurait-elle des amis « bien de chez nous » qui pourraient susciter un dialogue et rappeler que certains jugements culturels d'ailleurs ne sont pas acceptés ici - et sont punissables ? La solution est toujours plus difficile à trouver quand on est en face d'une famille isolée et insuffisamment intégrée.

S'agissant d'un jeune et avec son accord autant que possible, on peut prendre contact avec d'autres qui le connaissent : professionnels de santé, assistants sociaux, éducateurs et enseignants, moniteurs portifs, pour bénéficier de leur évaluation de la situation. S'adresser aux consultations disposant de compétences transculturelles spécialisées. Au plan général, les avis de spécialistes de la dangerosité sont évidemment importants ; penser aussi aux services de médecine des violences de certains hôpitaux. Se rappeler qu'on est toujours plus intelligent à plusieurs.

Dernière remarque : on peut dire qu'il vaut mieux prévenir trop que pas assez ; il est vrai aussi que, selon le groupe culturel, des démarches officielles ont un effet de dynamite... avec des risques de générer violence et chaos intra-familial supplémentaires. Alors, mettre en oeuvre ce qui peut être fait avant des interventions/intrusions extérieures, mais en évaluant

le risque que le drame survienne pendant qu'on temporise...

La question (grave) est : quelle est dans ce cas la bonne application du principe *Primum nil nocere* ?

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INTENSIVE COURSE ON ETHICS OF REPRODUCTIVE TECHNOLOGIES

Date & Location:
Leuven, Belgium, 13-15 November 2013

Organised by: Erasmus Mundus Master of Bioethics
Centre for Biomedical Ethics and Law Faculty of
Medicine KU Leuven, Belgium

Coordinator: Kris Dierickx, PhD
Keynote speaker: Prof.Dr. Andé van Steirteghem, MD,
PhD, Centre for Reproductive Medicine, University
Hospital Brussels

Staff: Yvonne Denier, PhD
Centre for Biomedical Ethics and Law, KU Leuven
Koen Devriendt, MD, PhD
Department of Human Genetics, KU Leuven
Thomas D'Hooghe, MD, PhD
Leuven University Fertility Centre, KU Leuven
Kris Dierickx, PhD
Centre for Biomedical Ethics and Law, KU Leuven
Bart Hansen, PhD
Centre for Biomedical Ethics and Law, KU Leuven
Willem Ombelet, MD, PhD
Department of Obstetrics and Gynaecology, ZOL,
Genk
Paul Schotsmans, PhD
Centre for Biomedical Ethics and Law, KU Leuven
Uschi Van Den Broeck, PhD Researcher in
Psychology
Leuven University Fertility Centre, KU Leuven

Objectives:
Reproductive medicine seems to have no limits: in vitro fertilisation, pre-implantation genetic diagnosis, rerogenetics, cloning, stem cell research, third party reproduction, etc. These medical possibilities or promises, however, are not without ethical and social implications. The objective of this course is to focus at some of the most challenging ethical issues in reproductive medicine, as well on the level of fundamental notions as applied clinical questions.

Participants:

The course is of interest to participants from diverse professional backgrounds, such as medicine, fertility, genetic counselling, ethics, law, philosophy and theology, health care administration, bioethics committees, and PhD students undertaking courses of study in these areas.

The intensive course Ethics of Reproductive Technologies is part of the Erasmus Mundus Master of Bioethics programme organised by a consortium of three European universities, namely the KU Leuven (Belgium), Radboud Universiteit Nijmegen (The Netherlands) and the Università degli Studi di Padova (Italy). Because of this combination, participants of the intensive course Ethics of Reproductive Technologies, will join Master students from all over the world.

Price:

The course fee will be € 650 if you register and pay as a participant before September 15th 2013, € 750 for payment from September 15th 2013 onwards. This fee includes tuition and course materials, as well as refreshments, three lunches and a dinner. Detailed information on registration and payment can be found at our website www.masterbioethics.org under Intensive Courses.

Information:

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ANNOUNCEMENT

HANS JOACHIM SCHWAGER AWARD

For more information see:

http://clinical-ethics.org/hjs_award_ceremony.html

We hope to receive applications from all over Europe and beyond acknowledging the clear focus of the Award on CLINICAL ETHICS.

The Award Ceremony shall be embedded in the context of ICCEC 2014, Paris (more information about the conference: <http://clinical-ethics.org>)

Prof. Dr. Stella Reiter-Theil
Jury President Hans Joachim Schwager Award

s.reiter-theil@unibas.ch

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EACME PRIZES

The European Association of Centres of Medical Ethics awarded two EACME-prizes of 500 Euros in the context of the upcoming EACME conference in Bochum. The EACME prizes were awarded to:

Caroline Brall

Institut für Medizinische Ethik und Geschichte der Medizin Ruhr-Universität, Malakowturm, Markstr. 258a
44799 Bochum, Germany

for her scientific contribution "*Personalised Medicine and Public Health. An Ethical Account on the Basis of Public Health Ethics Frameworks*".

Marco Annoni

Campus IFOM-IEO, Via Adamello 16,
Milan 20139 ITALY

for his scientific contribution "*Integrating Personalized Medicine and Person-Centred Medicine: Lessons and Directions from the Recent Search for Biomarkers of Placebo Response*".

This was the result of a fully blind review procedure within the Daily Board of EACME. Our President, Professor Renzo Pegoraro, will present the EACME prize officially during the conference in Bochum.

Congratulations to both EACME-prize winners!

DEADLINE NEXT NEWSLETTER

Deadline for the third edition of 2013:

November 15, 2013

If you wish to promote an event, or to inform your EACME-colleagues about the results of your work, descriptions of projects, book reviews etc. Any good ideas?

Don't hesitate to contact our editor Rouven Porz or Angelique Heijnen: rouven.porz@insel.ch or a.heijnen@maastrichtuniversity.nl

ANNOUNCEMENTS

UNESCO Chair in Bioethics 9th World Conference BIOETHICS, MEDICAL ETHICS & HEALTH LAW Towards the 21st Century

Royal Continental Congress Center, Naples, Italy
November 19-20-21, 2013.

For further information, please visit the website:
www.isas.co.il/bioethics2013

NURSING ETHICS

Intensive Course on Foundational Approaches, Contemporary and Educational Issues in the Field of Nursing Ethics, Leuven, Belgium, 3 - 6 Dec 2013

Coordinator: Prof. Chris Gastmans, PhD
Keynote Speaker: Prof. Per Nortvedt, PhD, Oslo

Objectives: The objective of the course is to foster exchanges on foundational and methodological approaches as well as on contemporary and educational issues in nursing ethics.

Format: This course works from an interdisciplinary (philosophical, theological, nursing, clinical-ethical) perspective. During the course, national and international experts will give presentations on various topics in the domain of nursing ethics.

Participants: The course is of interest to participants from diverse professional backgrounds, such as nursing, medicine, philosophy and theology, health care administration, and PhD students undertaking courses of study in these areas. The intensive course Nursing Ethics is part of the Erasmus Mundus Master of Bioethics programme organised by a consortium of three European universities, namely the Katholieke Universiteit Leuven (Belgium), Radboud Universiteit Nijmegen (The Netherlands) and the Università degli Studi di Padova (Italy). Because of this combination, participants of the intensive course Nursing Ethics, will join Master students from all over the world.

Price: The course fee will be € 775 if you register as a participant before October 15th 2013, € 875 for registration from October 15th 2013 onwards. This fee includes tuition and course materials, as well as refreshments, four lunches, a dinner and a concert in the Concert hall of Bruges. Detailed information on registration and payment can be found at our website www.masterbioethics.org under Intensive Courses.

Information:

Chris Gastmans PhD and Chantal De Keersmaecker

E-mail: Chantal.dekeersmaecker@med.kuleuven.be

Journal of Medical Law and Ethics (JMLE)

The Journal of Medical Law and Ethics (JMLE) aims to publish excellent quality peer-reviewed articles, reports, case notes and essays in the field of medical law and ethics, which is a very exciting and controversial area of law.

This journal aims to focus in particular on the legal and ethical aspects of medicine.

This is an opportunity for the increasing number of academics and practitioners alike to discuss the most controversial areas of medical law, to present research, to analyse and criticise the law, and hopefully aim to improve the way that medical care is provided.

See: <http://jml-online.com/>

Call for Papers for a Special Issue with Ethics and Information Technology on "ICT4PEACE"

Humanitarian organizations and UN agencies are increasingly responding to disasters, implementing peacekeeping operations and deploying post-conflict reconstruction teams in environments where information and communication technologies play a pivotal role, providing an ocean of data to be sorted, analyzed and addressed. Victims now have access to communication tools and, primarily via mobile networks, are empowered to exchange information, help each other and themselves, in addition to being able to provide valuable data to humanitarian responders, peacekeepers and actors in conflict situations. There has been a fundamental shift from top-down hierarchical information structures to bottom-up communication at all levels of humanitarian response. This increased use of ICTs including SMS, crowdsourcing, social media, twitter and GIS have opened a new vista with countless positive benefits for humanitarian response. However, many of the key questions and issues require further research and analysis to assess both the up and downsides to this new reality. Thought needs to be put into developing practical solutions to the challenges of using ICT in difficult environments, in particular fragile states, and what kind of protection and ethical guidelines are required to ensure the "do no harm" principles of humanitarian organizations. This paper series will

explore the ethical issues surrounding the use of ICT in an age of digital humanitarianism.

- In the urgency that surrounds and humanitarian response to natural or man-made disasters, how can the innumerable bits of data be validated and checked to ensure effective help to victims?
- How can effective safety and privacy protection mechanisms be balanced with the need to exchange information openly and quickly?
- What does it mean in ethical terms if anyone can provide information, anyone can act on information, anytime, anywhere?
- What kinds of Ethical Guidelines are needed to ensure that do no harm principles are upheld?
- How can system design integrate ethical concerns during emergency response, peacekeeping operations, and post-conflict reconstruction?
- What are the ethical concerns surrounding Big Data and digital humanitarianism?
- What are the ethical implications of new technologies such as crowdsourcing, social media?

This series seeks papers that explore ethical issues related to the use of ICT in crisis response, peacekeeping and post-conflict reconstruction both from a policy development and system design perspective. What kind of processes, systems or new technologies could be useful to address some of the issues outlined above?

The editors at Ethics and Information Technology are seeking articles for a special issue in this area. Submissions will be double-blind refereed for relevance to the theme as well as academic rigor and originality. High quality articles not deemed to be sufficiently relevant to the special issue may be considered for publication in a subsequent non-themed issue.

Closing date for submissions: September 30, 2013

To submit your paper, please use the online submission system, to be found at www.editorialmanager.com/etin

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