

EACME Newsletter

European Association of Centres of Medical Ethics

Executive Office: Angelique Heijnen
Maastricht University, Dept. Health, Ethics and Society
Faculty of Health Medicine and Life Sciences
P.O. Box 616
6200 MD MAASTRICHT, THE NETHERLANDS
Tel: +31 43 3882145
Fax: +31 43 3884171
A.Heijnen@maastrichtuniversity.nl
www.eacmeweb.com



Number 37 – September 2014

CONTENTS

Editorial	1
R. Porz	
CME Lille	2
Some Plenary Appetizers	4
Assistance à la Vie en France	6
D. Jacquemin	
A new legislative proposal on assisted suicide in Germany	8
A. Salkic	
Soins palliatifs et fin de vie – un ouvrage important	9
J. Martin	
Will medical ethics survive?	10
R. Nicholson	
Global Advance Care Planning Conference	11
R. Jox	
Being in dialogue with colleagues and clinics across countries	11
J. Bresson Ladegaard Knox	
Bioethic at the movies	13
K. Schmidt	
Recensions	15
Visiting researcher at the Ethox centre	16
L. Mahieu	
Deadline next Newsletter	17
Editorial Board	17

EDITORIAL

Vulnerability ?!

Dear friends, this year the EACME conference will be held in Lille, France from October 2nd – 4th. The topic of the conference is: *frailty, vulnerability and social participation*. Thus the conference deals with issues of conflict between ethically possible and ethical demanded ways of handling disability, an ageing society, psychiatric disorders etc.

Personally – as a big supporter of care ethics and feminist approaches to bioethics – I deem it extremely important, that an ethics conference approaches these topics with new glasses or lenses. Not only taking the perspective of a self-determined, autonomous individual, but adopting a perspective of interaction in society and social inclusion. These social circumstances can be related to members of the society which are not that self-determined and autonomous as the ideal of self-determination might pretend. Vulnerability as a change in mind-set to autonomy. It has often occurred odd to me that autonomy is such an undefined, often unquestioned ideal in Western ethics. Unfortunately, I am afraid that the lack of definition might also slip into the concept of vulnerability. To put it simple: Suddenly, everyone is highly vulnerable!

Sure, pregnant women are vulnerable, handicapped are vulnerable, research participants are vulnerable. What does it mean in particular? Who is in charge of the decision? Did anyone make the effort to ask these people if they really feel 'vulnerable'? Or is vulnerability now degenerating to a description (gradation!) of those who we perceive as particularly needy and worthy of protection? Might be true, but please mind: This is almost discriminating!

That's all from my side, I am looking forward to the discussions in Lille. As an „appetizer“ we already present you some plenary speakers' thoughts in this newsletter – hot off the press. Moreover, this time we have so many exciting and meaningful contributions, that I cannot name them all. I only want to highlight one author: Richard Nicholson. He gives an impressive perspective of medical ethics in the context of global climate change – intriguing, but worrying at the same time.

Enjoy our Newsletter, Rouven Porz, Editor

rouven.porz@insel.ch

CENTRE OF MEDICAL ETHICS (CME) LILLE

Host of the annual EACME conference 2014

Since its beginnings in 1984, the Centre of Medical Ethics (CME) has contributed to the development of the university sector of bioethics in Europe, notably as co-founder of the European Association of Centres of Medical Ethics (EACME, 1984) and, more recently as a member of the European Clinical Ethics Network (ECEN, 2005).

Organised as a research team in 1988, the CME corresponds to one of Lille Catholic University's priorities in developing an interdisciplinary research program in ethics, co-ordinated within the ethics department of the university itself (of which the CME is a member) along with the Center for research into the Ethics of Economics and Enterprise (C3E) and the Center of Family Ethics.

The CME offers and coordinates several courses and training programs :

- Lectures given to medical and paramedical students
- Courses to health professionals in continuing education
- University diplomas in health ethics (DUES) and in palliative care (DUSP and DIUSP)
- Since 2013, two masters in health ethics (the first in public health (University Institute Health and Society) and the other for the Philosophy Institute)

As a centre for **interdisciplinary research** on ethical and philosophical questions raised by the development of knowledge and practices in the field of medicine and, more broadly, of health, CME falls within a **context-based** and **pragmatic** perspective, that is to say, in an experience-based approach with health care actors in which ethics is fundamentally designed as a collective

learning process.

CME's research **goals** are:

- To better understand the ethical questions raised by the development of contemporary medicine and health care systems;
- To develop, in conjunction with health care actors, methods which would allow us to better understand these issues and to change their practices based on this questioning;
- To investigate the theoretical framework of this approach in the hopes of coming to a better understanding of the collective learning process that defines ethics in this perspective.

Furthermore, CME's research work develops two interconnected lines of research, dealing respectively with:

1. The tools necessary for an ethical approach;
2. The empirical scope of the care, accompaniment and support for vulnerable people.

Since 2008, in addition to work focusing on end-of-life issues and the elderly, CME invested in a new thematic scope – the relationship between disability and social participation. Investing in different areas (aging, end of life, disability and mental health), fragility and human vulnerability seem a particularly relevant means of developing support for setting out the pragmatic dimensions of an ethical approach.

1: Tools for an Ethical Approach

1.1: Ethical intervention research

The development of bioethics addresses a social issue in the field of health, particularly in the form of intervention in clinical ethics, which has become today, including all over Europe, a common means of intervention as well as a theoretical and methodological research challenge.

These practices are an opportunity for theoretical debates and empirical research which address not only the ethical approaches taken but also the goals of these practices, the intervention methodologies as well as the appropriate assessment methods.

In this particular field, CME has developed both a body of practice and a specific theoretical framework (neither a clinical ethics centre nor an ethical space but something that instead addresses the development of an institutional ethics perspective).

Achievements

An institutional ethics perspective led to collaboration with several French hospitals and to the release of two reference works: Jean-Philippe Cobbaut's doctoral thesis, *Bioéthique et réflexivité* [Bioethics and reflexivity]

(Cobbaut, 2008), and the compilation of an issue for the *Journal International de Bioéthique / International Journal of Bioethics*, titled “De l'éthique clinique à l'éthique institutionnelle” [“From Clinical Ethics to Institutional Ethics”] (Boitte, Cobbaut, 2012).

Prospective outcomes

The current work consists of:

Developing:

- new tools in clinical ethics,
- a new method for contextual analysis in ethics and response protocol for care institutions;
- Extending these tools into the field of medical and social institutions;
- Developing a validated assessment method.

1.2 Ethics teaching research

In the pragmatist approach to ethics that we are developing, intervention, research and training are interdependent and revolve around the concept of learning. The challenge of researching how ethical practice is taught concerns determining how to go about testing new methods of training that focus on assuring that actors carry out their activities effectively in context, and determining how we can learn from this and build the conditions needed for organisational learning that develops collective skills (for actors and organisations alike) that are essential in changing practices.

Achievements

Grégory Aiguier's doctoral thesis, which is currently being finalised and which has been carried out as part of a cooperative project with the Institute of Health and Society at UCL, Belgium, investigates the foundations and educational implications of a pragmatist turning point in ethics that saw ethics as an experience-based and reflective learning process for actors and organisations in which one must think about procedures (methods, teaching positions, measures and governance).

Prospective outcomes: teaching experiments

The Interreg IV “Dignity in care” Project (2011-2014) provides an opportunity to assess the relevance of ethics training for students and professionals in the health care sector through simulation training activities in the sTimul teaching lab. It will be extended as part of a call for projects (“Horizon 2020”) which is meant to define the procedures for setting up a learning lab that helps expand work experience-based reasoning and develop enabling environments that bring together technological, social and educational innovations (*Interreg EDECT Cluster 2014-2015*).

1.3. Research approach in the topic of ethics

CME's pragmatic and context-based perspective involves an epistemological approach to providing an interface between reflecting on practical reasoning and

normativity and determining how to carry out empirical research that reflects the results of the ethical approaches taken and their learning outcomes.

Achievements

In this context, the CME seminar (the 2011-2012 and 2012-2013 seminar titled “Vulnerability and Pragmatism”) sought to take a better approach at the vulnerability of human action as a condition necessary for the internalist emergence of a dynamic process of learning and transformation for those involved in order to resolve ethical questions (by analysing pragmatic criteria of moral philosophy but also by comparing a number of ethical experiments). Through a joint seminar, several research activities and work on emancipatory research, particularly in the two-year Masters programme in Social Health Care which began in September 2013 with the so called *HaDePas*¹ research unit, we are continuing work on the methodology of research in ethics.

Prospective outcomes

A continuation of the Vulnerability and Pragmatism seminar in 2013-2014/2014-2015 on our intervention methodologies with the idea of publishing a theoretical and methodological piece of work titled “For a Reflexive Governance of Bioethics”; Testing new approaches for social innovation in health care within the two-year Masters programme in Social Health Care (“Ethics, Institutions and Health Care” study track).

2: Empirical Areas of Research

Since 2008, in conjunction with the development of the “Disability, Dependence, Citizenship” cluster at Lille Catholic University, we have decided to focus our research in the field of disability and dependence.

In continuation of our work on clinical research (Host Team 4031) and on ethics in care institutions, the approach to care and support for vulnerable people is a field that allows us to highlight the pragmatic challenges and the connections between the relationship of care, organisations and health policies. In addition to the work that has been carried out on the topic of the elderly and end-of-life issues over many years, CME has extended its research to the area of people with mental and physical disabilities.

Two theses have looked across the board at these issues: one on bereavement and supporting those in mourning (Rozenn Leberre, defended in November, 2013), and the other on the presence of those most

¹ An interdisciplinary research unit in the Humanities and Social Sciences which stands for “Handicap, Dépendance et Participation sociale” [“Disability, Dependence and Social Participation”].

vulnerable in human evolution (David Doat, defence expected in December, 2014). These fields have been studied from the perspective outlined above through collaborative research processes with those involved in the field.

2.1. Aging and the elderly

In recent years, work concerning the elderly has developed around people with Alzheimer's disease (in the health institutions of CHRU Lille, EREMA and CSI Paris Tech), their support and their care pathway. The work opportunities are structured around in-home care, the support intervention of *MAIA* ("Home for Alzheimer's Patients' Autonomy and Integration") and proper treatment through collaborative work with several *MAIA* homes in the Lille region and a doctoral thesis on the ethical issues of care relationships in an institution (in this case, the nursing home) by Alice Lancelle, whose thesis drew especially from the theoretical notion of "community care", as developed in particular by Micah Hester (Hester 2001).

2.2. Palliative and end-of-life care

Palliative care has been a CME development focus since the end of the 1980s. Education and training programmes all the way up to the Masters level and a reference manual whose third edition was just released in 2014 bear witness to this. In this area, the essential specific area of work is that of the decision making process in the case of resuscitation, in the application of the Léonetti law in palliative care and in the view of enabling and "empowering" patients.

2.3. Disability and social participation

This area of research has been developed in recent years in collaboration with the *HaDePas* research unit. Through this, we have focused more specifically on user participation in the processes that affect users with a view towards developing emancipatory research with an international network (Geneva, Namur, UQAM, etc.). This work is accompanied by thorough reflection on the place and the recognition of people with disabilities (David Doat) and the support they receive (thesis in preparation, Anne Rizoulières).

2.3. Mental health

Contemporary psychiatry has seen some profound conceptual, contextual and institutional changes over the years as it moves towards the so-called mental health model which addresses mental disorders, both in the consequences it has for the patient's personality as well as in its relationship to the patient's living environment. As part of this development, ethical reflection and its institutionalisation have to deal with new actors (the users and their families as well as other actors, including the legal world, local powers, etc.) and new environments because of deinstitutionalisation and reterritorialisation. The prospective outcomes in this

area are support for institutions, a thesis on mental health care (Guillaume François) and participation in an ANR 2013-16 CONTRAST contract ("From Coercion to Consent").

SOME PLENARY SESSION 'APPETIZERS'

Régis AUBRY

Dans une société vieillissante : les personnes âgées, des partenaires jusqu'au bout?

A la croisée des avancées rapides et considérables dans le champ de la santé, du développement des droits des personnes et en particulier des personnes malades, et des contraintes économiques et budgétaires, se pose la question, dans notre société vieillissante, de la place des personnes âgées.

Parler de progrès dans le champ de la santé ne se limite pas à constater que nous sommes de plus en plus nombreux à pouvoir vivre de plus en plus longtemps, sans maladie et sans handicap. Les avancées techniques et scientifiques de la médecine seront un progrès si elles sont associées à un véritable accompagnement par notre société de ces nouvelles figures de la fin de vie que sont les personnes qui peuvent aujourd'hui vivre longtemps avec une maladie (ou plusieurs) qui ne peut guérir et impacte non seulement la qualité mais le sens même de la vie. Il apparaît ainsi que la possibilité de pouvoir choisir le lieu qui fait sens à la fin de sa vie est assez limitée, voire impossible dans certaines situations de perte d'autonomie physique ou psychique.

Le rapport 2013 de l'Observatoire National de la Fin de Vie interroge à la fois la question de l'autonomie et celle de la liberté des personnes âgées à la fin de leur vie. Il constate que les Etablissements d'Hébergement pour Personnes Agées Dépendantes (EHPAD) concentrent en quelque sorte, à notre époque, toutes les personnes, de plus en plus nombreuses, qui du fait de leur âge et des maux associés, ne peuvent plus exercer leur autonomie du fait d'une inadaptation de l'environnement à leur propre évolution. Il souligne la tendance française à la médicalisation de la fin de la vie et à l'hospitalisation extrêmement fréquente des personnes du fait de l'approche de la mort. Ce rapport montre combien cette évolution sociale et démographique matérialise un impensé de notre société, croise la question du respect du droit des personnes, en particulier celui des personnes en fin de vie.

Il est nécessaire aujourd'hui de penser l'accompagnement des personnes âgées sous un angle différent, en termes de nouvelles formes de solidarité, en termes de redéfinition de la question du sens de la

vie. Nous sommes en effet à une époque où la valeur de la vie semble de plus en plus corrélée à la capacité d'agir de l'homme. Dans un contexte économique très contraint, le regard sur les personnes qui présentent des incapacités ou une dépendance pourrait conduire à une forme d'irrespect des personnes vulnérables.

Régis Aubry Professeur associé de médecine palliative, université de Franche Comté . Coordinateur de l'axe de recherche "Éthique et Progrès Medical" du CIC 1431 Inserm, Centre Hospitalier Régional Universitaire, Besançon, France. Membre de l'Équipe d'Appui 2274 Logiques de l'Agir - Laboratoire de Recherches Philosophiques sur les Sciences de l'Action – à l'UFR Sciences du Langage, de l'Homme et de la Société depuis 2012 (directeur : Pr Thierry Martin).

raubry@chu-besancon.fr

Pierre BOITTE

Which bioethics for an inclusive society? For an ethics of social participation including dependent and disabled people

Main point: Strong need to recognize our changing perceptions of dependent and disabled people that require new ways of thinking about care and organized support that there are for these people.

Some questions (i) How to develop participation of those involved, not only in decision-making but, more broadly, in defining a care plan or a life plan? (ii) What are the conditions of an ethics of participation which has the task of working with those concerned?

Pierre Boitte is an ethicist in the field of health, with a background in sociology and philosophy and a PhD in Public Health-Bioethics. He is Professor in Medical Ethics at the Medical School and the Centre of Medical Ethics, Catholic University of Lille.

pierre.boitte@univ-catholille.fr

Chris GASTMANS

Dignity-enhancing care for persons with dementia : a foundational and clinical ethical framework

The number of older people continues to increase worldwide. Given that older people are especially prone to suffer from dementia, many countries will be confronted with a rising number of people with dementia. This demographic evolution has increased clinical interest in the early diagnosis of dementia. These demographics as well as clinical evolutions result in important new responsibilities for older people, in general, and people suffering from dementia, in particular. What do they consider to be good care and a good death for persons with dementia? What do they consider as their own responsibility in 'preparing the

future'? What do they think about legal regulations regarding patient rights, advance directives, euthanasia, and assisted suicide, and what do these legal frameworks mean for their own situation? In our contribution, we propose a comprehensive foundational and clinical ethical framework to deal with the above-mentioned questions about care for persons with dementia. First, we briefly outline the general philosophical-ethical background from which we developed our framework. More particularly, a wider ethical perspective characterized by three aspects is presented: lived experience, interpretative dialogue, and normative standard. Against this background, we identify and explore three cornerstone concepts that must be observed in an ethical approach to dementia care: vulnerability, care, and dignity. Based on these concepts, the ethical essence of dementia care practices is described as 'providing care in response to the vulnerability of a human being in order to maintain, protect, and promote his or her dignity as much as possible.'

Chris.Gastmans@med.kuleuven.be

Full Professor of Medical Ethics in the Faculty of Medicine, KU Leuven.

Centre for Biomedical Ethics and Law, Leuven – BELGIUM

John Stewart GORDON

A Disability Conscious Bioethics

Following Alicia Ouellette, there is currently no well-developed disability-conscious approach to bioethics. However, whether it is eventually possible to overcome what some scholars have coined a "civil war" between bioethicists and disability scholars and activists remains to be seen. In any case, both camps must change and it seems necessary that scholars and activists contributing to the lively debate must more deeply engage with the opposing perspective in order to gain a better understanding of the concepts as well as to acknowledge the biases and fears of the other side. The goal of the talk is twofold, first, to highlight the different perspectives of bioethicists and members of the disability rights community and to show - based on the different history and theoretical underpinnings of bioethics and disability studies - that they do not share a common ground of understanding. Second, it will be examined whether the admittedly far-reaching claim to abstain from adhering to the important idea of autonomy and the related question of personhood (and moral status) - that causes vital problems for the disability rights community - might be a first start for a mediating approach between both camps.

John Stewart GORDON : University of Cologne Faculty of Human Sciences; Department of Special Education and Rehabilitation Cologne, Germany
jgordon@uni-koeln.de

W1 Professor for Anthropology and Ethics in Rehabilitation Sciences with Special Consideration of People with Disability; Co-director of the Hans Jonas–Institute; Permanent Visiting Professor at the Department of Philosophy at Vytautas Magnus University Kaunas

Micah HESTER

A pragmatic account of vulnerability in health care

While all human beings, by virtue of their finitude, are vulnerable, each of us is vulnerable in unique ways given certain conditions and contexts. Patients are, as Richard Zaner tells us, “peculiarly vulnerable” in the face of their injuries/illnesses and the power and authority of healthcare providers. This asymmetry at the heart of patient-provider relationships demands of providers a moral response to patient vulnerability. I suggest that three responses are possible: acquiescence, protection, or empowerment. I argue that acquiescence by healthcare providers is acceptable, even necessary, under a certain conditions, but that acquiescence is best understood as giving in, not giving up. A protectionist response is also warranted on occasion, but I suggest that it is best taken up as our *modus operandi* in relation to vulnerable populations and policy. Finally, I argue that empowerment, taken broadly, can encompass conditions calling for either acquiescence or protection, but also keeps focus on overcoming, not simply living with, vulnerabilities.

Biography: D. Micah Hester, PhD, is Chief of the Division of Medical Humanities and Professor of Medical Humanities and Pediatrics at the University of Arkansas for Medical Sciences (UAMS) in Little Rock, Arkansas (USA). He is also clinical ethics consultant at UAMS and Arkansas Children’s Hospital. He is author/editor of nine books and numerous journal articles, including *Community As Healing* (Rowman & Littlefield, 2001) and *Guidance for Healthcare Ethics Committees* (Cambridge UP, 2013).

DMHester@uams.edu

Jackie Leach SCULLY

Disability and Vulnerability: on bodies, dependence and control

The idea of vulnerability is in fashion in bioethics. But why do certain groups of people count as vulnerable, and who decides? This keynote address looks critically at the way that disabled people are routinely considered to be more vulnerable than nondisabled people, in clinical and research contexts. In it, I’ll be challenging some widely held assumptions about disability, vulnerability, dependence and autonomy.

Professor Jackie Leach Scully:

jackie.scully@newcastle.ac.uk

Co-Director, Policy Ethics and Life Sciences Research Centre and Professor of Social Ethics and Bioethics, Newcastle University

Guy WIDDERSHOVEN

An inclusive bioethics for an inclusive society

For an inclusive society, we need an inclusive bioethics. This means that there should be room for the voices of people with disabilities. In the first place, an inclusive bioethics requires specific methodologies to empower people who are not automatically included in moral discourse. Whereas bioethics in the past has proven to be effective in including the voice of the (well-educated and competent) patient, and that of the (well-trained and professional) nurse, nowadays new steps are necessary to include vulnerable patients and caregivers who are not less educated (family, informal caregivers). Ethicist should not speak on behalf of these groups, but enable them to speak for themselves. This requires further development of egalitarian and democratic techniques, such as Moral Case Deliberation. In the second place, an inclusive bioethics will have to develop concepts which enable us to do justice to the situation of people with disabilities. Whereas in the past, bioethics has succeeded in changing medical ethical discourse by introducing new concepts, such as autonomy and justice, nowadays these concepts are in need of reinterpretation. Promising in this respect is the concept of relational autonomy and the capabilities approach to issues of justice. By combining methods and concepts which are sensitive to the specific needs of people with disabilities, bioethics can help to create conditions for an inclusive healthcare.

Guy Widdershoven is Professor of Philosophy and Ethics of Medicine and Head of the Department of Medical Humanities at VU University Medical Center, Amsterdam. He is also senior researcher in the EMGO Institute for Health and Care Research. His research focuses on dialogical approaches to empirical ethics and clinical ethics consultation in longterm care (psychiatry, elderly care, care for people with an intellectual disability): g.widdershoven@vumc.nl

ASSISTANCE A LA FIN DE VIE EN FRANCE

Lorsqu’une nouvelle modalité d’assistance à la fin de vie « se construit » peu à peu en France...

Depuis l’élection de François Hollande comme président la République Française, une volonté politique est affichée de proposer, dès juin 2014, une nouvelle loi relative à la fin de vie. C’est dans cette

perspective que fut sollicité le rapport Sicard en décembre 2012, puis l'avis 121 du CCNE de juillet 2013 « *Fin de vie, autonomie de la personne, volonté de mourir* », proposant un vaste débat démocratique au niveau des régions en vue d'étayer ce que pourrait recouvrir une nouvelle législation. Première interrogation éthique, celle d'une législation annoncée -élargir la loi Léonetti à une prise en charge « plus active » de la fin de vie-, sous-tendue par une construction temporelle et politique ouvrant à une euthanasie qui pourra ou non en porter le nom ; se trouve-t-on encore dans ce qu'on peut appeler un débat démocratique?

S'il n'est pas possible actuellement de présumer de ce que sera cette « loi de juin 2014 », le rapport Sicard semble préparer les esprits à deux possibilités : la sédation terminale et le suicide assisté. Considérons les questions ouvertes par ces deux propositions.

Tout d'abord, la sédation terminale est envisagée comme un geste létal dans les phases ultimes de l'accompagnement en fin de vie : « Lorsque la personne en situation de fin de vie, ou en fonction de ses directives anticipées figurant dans le dossier médical, demande expressément à interrompre tout traitement susceptible de prolonger sa vie, voire toute alimentation et hydratation, il serait cruel de la "laisser mourir" ou de la "laisser vivre", sans lui apporter la possibilité d'un geste accompli par un médecin, accélérant la survenue de la mort. » Dans ce paragraphe, la demande du malade est compatible avec la loi Léonetti mais les expressions « laisser vivre » et « laisser mourir » sont ambiguës et risquent fort d'être « hors la loi » si elles sont comprises comme un « laisser d'abandon ». La loi rappelle en effet à plusieurs reprises que « le médecin sauvegarde la dignité du mourant et assure la qualité de sa fin de vie en dispensant les soins visés à l'article L. 1110-10 ». Dans le rapport, il est dit que le geste possible est « accompli » par un médecin. Cette notion d'accomplissement renforce, de notre point de vue, l'intentionnalité du geste. Ne sommes-nous pas ici dans les conditions d'une « euthanasie » au sens de la définition issue de la loi belge : « il y a lieu d'entendre par euthanasie, l'acte pratiqué par un tiers, qui met intentionnellement fin à la vie d'une personne à la demande de celle-ci »?

Et c'est à ce propos qu'il importe de s'interroger : que signifierait, tant pour les professionnels que pour l'imaginaire collectif, un geste qui, sans être qualifié d'euthanasie, permettrait de « construire » la mort d'un patient à sa demande ? N'est-il pas à craindre qu'un geste, même si l'intention argumentée peut s'avérer juste et droite, puisse induire, dans le contexte social, certes une culpabilité morale du professionnel mais, plus radicalement encore, une confusion de sens dans

les gestes et intentions proposés par la médecine qui, tout en même temps, « soulagerait » en ayant conscience de mettre fin à la vie de celle, celui qui lui est confié ? Comment s'y retrouvera-t-on aujourd'hui ? Bien sûr, ces questions ne sont pas simples cliniquement et moralement mais invitent à interroger ce qui pourrait en résulter si le débat ne se fait pas « au grand jour », à l'image d'autres questions concernant aujourd'hui la société française. En effet, la construction de la mort de l'autre via la « sédation terminale » est-elle réellement différente de l'euthanasie -si ce n'est sa dilution temporelle et morale- lorsqu'il s'agit de mettre un terme à la vie d'un patient à sa demande?

Considérons l'autre piste de réflexion ouverte par le rapport Sicard : le suicide assisté. Envisageant conjointement les « avantages et inconvénients » du suicide assisté, le rapport ne se prononce pas sur la pertinence d'introduire ou non une assistance au suicide en France. Ce n'est donc pas au sens strict une proposition. En revanche, si le législateur ouvrait cette possibilité, la commission affirme « l'impératif d'impliquer au premier chef la responsabilité de l'État et la responsabilité de la médecine ». Cela implique la nécessité de s'assurer de la volonté et de la liberté de la personne avec des échanges collégiaux associant le patient, la famille, le médecin traitant, un autre médecin externe et un soignant. Cet engagement de la médecine ne se limite pas à ces étapes préalables. Lors de l'ingestion du produit et de l'agonie, la présence du médecin traitant ou, en cas d'objection de conscience, du médecin prescripteur est jugée nécessaire.

Et c'est ici que d'autres questions s'avèrent nécessaires à ouvrir. L'État doit-il s'engager dans des démarches visant à offrir la possibilité à certains citoyens de se suicider ? Sur le plan sociétal, nul ne sait quelles seront les conséquences d'une ouverture vers le suicide assisté. Cette incertitude concerne les patients vulnérables, en doute sur la valeur de leur existence. Elle s'applique aussi aux solidarités familiales et collectives, parfois défaillantes dans notre société. Si le législateur ou l'État autorise une assistance au suicide sous certaines conditions, quelle sera la place pour la médecine et les soignants?

La commission Sicard juge insatisfaisantes les procédures légales étrangères. Elle s'interroge sur la vérification de la liberté des personnes demandeuses, la prise en compte d'une détresse psychique, la présentation d'alternatives au suicide, l'investissement militant des associations. Pour contrebalancer ces lacunes, la médecine apparaît comme le protagoniste à impliquer pour entendre, réguler, mettre en œuvre et contrôler le suicide assisté. Mais n'est-il pas excessif et injustifié de confier l'assistance au suicide

uniquement à la médecine alors que cela ne correspond classiquement pas à ses repères ? N'est-ce pas une certaine démission de l'État qui utiliserait la médecine comme bouclier, bras armé et arbitre ? En langage simple, tout relève-t-il de la médecine ?

Si le législateur prend et assume l'initiative d'ouvrir une assistance au suicide, il nous semblerait plus juste de construire une procédure qui engagerait la responsabilité du demandeur, de la société civile, de l'État et de la médecine. Le citoyen ne doit-il pas assumer sa conception de l'existence dans la limite de ce qui lui est possible ? L'État doit exercer son rôle de protection du vulnérable et de garant des lois. La médecine doit perdurer dans sa mission de prendre soin et d'accompagner la personne malade. Mais le soignant ne peut le faire que s'il se sent en adéquation avec ses repères professionnels et personnels.

On le voit, de nombreuses questions sont aujourd'hui ouvertes et, en l'état actuel des débats, rien ne présume que le législateur y prête réellement attention si, d'une certaine manière, la « cause est déjà entendue »

Dominique JACQUEMIN
Centre d'éthique médicale, Université Catholique de Lille
dominique.jacquemin@univ-catholille.fr

A NEW LEGISLATIVE PROPOSAL ON ASSISTED SUICIDE IN GERMANY

Under the current German legislation neither (attempted) suicide nor assisted suicide are considered punishable crimes. However, the legal situation regarding the duty to rescue and the use of sedatives is rather complex, containing legal uncertainties – especially for physicians. The physicians' professional code allows physician-assisted suicide in some federal states and prohibits it in others.

Not only for that reason, but also because of the rise of commercial assistance in suicide by an organization in Hamburg and the increasing “suicide tourism” to Switzerland, this is a highly controversial topic in Germany. Several attempts to finally establish a clear ruling, especially in order to ban commercial assisted suicide, already failed. However, by the end of the year 2014, the German Bundestag is supposed to debate a possible legal regulation of assisted suicide once again.

On that occasion, a group of experienced researchers in the fields of law, ethics and palliative care have

presented and published a Draft Bill on Assisted Suicide in their book “Selbstbestimmung im Sterben – Fürsorge zum Leben” (Autonomy in Dying – Care for Life) at the end of August 2014.

The main goals of the draft proposal are to provide transparency and legal certainty, to preserve patients' right to self-determination and simultaneously strengthen the protection of life – precisely to prevent a legalization of active euthanasia and social pressure on vulnerable individuals. International data show that these targets are best attained by legal provisions regulating the individual cases in contrast to a general interdiction of organized or commercially assisted suicide, as it was suggested by other proposals so far (for example: Bundestag printed paper no. 17/11126; Bundesrat printed papers no. 230/06, 515/12).

Contrary to the existing German law, the new proposal resembles the Oregon Death With Dignity Act and suggests to penalize those who assist a person to commit suicide, but with two important exceptions: (1) for relatives and closely related persons and (2) for physicians.

According to the proposal physicians would be able to legally assist in suicide for incurably ill people with a limited life expectancy under very strict conditions. Main requirements therefore are the verification of the patient's voluntary and well-reflected wish as well as the comprehensive and life-oriented information about all alternatives, in particular palliative care. Moreover at least another independent physician has to be consulted and a minimum of ten days has to pass between the informed choice and the prescription of drugs to commit suicide. Advertising services for assisted suicide of any kind shall be forbidden.

Another goal of the proposal is to prevent the approval of killing on request (active euthanasia) as well as assisted suicide for aged healthy people or mentally ill persons. At the same time hospices and palliative care shall be expanded. Data deriving from the duty of documentation is supposed to provide the first reliable assessment of the situation in Germany. In addition, there shall be a clarifying modification of the German Law on Narcotics (Betäubungsmittelgesetz).

Several members of the Social Democratic Party (SPD) have already expressed their sympathy with this proposal. The competing draft bills are either considerably divergent (prohibition of every organized form of assistance in suicide) or still in the pipeline. For the moment it is uncertain what the outcome of the legislative process will be or when to expect a final law, especially as this issue is treated by parliament as a matter of conscience with party whip being suspended.

The draft bill and its scientific foundation are available as e-book and in print (only in German) under the title "Selbstbestimmung im Sterben – Fürsorge zum Leben. Ein Gesetzesvorschlag zur Regelung des assistierten Suizids",

http://www.kohlhammer.de/wms/instances/KOB/appDE/nav_lpCategory.php?landingPage=Borasio_AssistierterSuizid

Authors:

Gian Domenico Borasio - Palliative Care Physician; Professor at the University of Lausanne

Ralf J. Jox – Palliative Care Physician and Bioethicist; Associate Professor at the University of Munich

Jochen Taupitz – Jurist; Deputy Chairman of the German Ethics Council and Managing Director of the Institute for German, European and International Medical Law, Public Health Law and Bioethics of the Universities of Heidelberg and Mannheim (IMGB)

Urban Wiesing – Bioethicist; Professor at the University of Tübingen

With contributions from:

Amina Salkić – Jurist; General Manager and Research Assistant at the Institute for German, European and International Medical Law, Public Health Law and Bioethics of the Universities of Heidelberg and Mannheim (IMGB)

For more information and references to this publication see:

http://blog.kohlhammer.de/wp-content/uploads/Pressemitteilung_Gesetzesvorschlag_assist_Suizid.pdf

Amina Salkić, LL.M.

amina.salkic@imgb.de

SOINS PALLIATIFS ET FIN DE VIE – UN OUVRAGE IMPORTANT

A propos de : G.D. Borasio : Mourir - Ce que l'on sait - Ce que l'on peut faire – Comment s'y préparer. Lausanne : Presses polytechniques et universitaires romandes, 2014, 155 p.

Gian Domenico Borasio, chef du service universitaire de soins palliatifs à Lausanne après l'avoir été à Munich, aborde dans cet ouvrage, très complet malgré sa concision, les dimensions liées à la fin de vie - médicales, physiques, psychosociales, spirituelles, juridiques - et les manières d'être meilleur aujourd'hui à ces égards. A propos d'attitudes est évoquée la vexation narcissique qu'est pour certains professionnels le fait qu'un patient meure. « Cette attitude de 'refus d'un échec' provoque des souffrances inutiles à bien des patients et leurs familles. ». S'agissant de bienveillance médicale et de fin de vie :

« La bienveillance ne revient pas à décider pour son patient mais à l'aider à prendre lui-même la décision la plus appropriée ». Parmi les angoisses répandues, il y a celles d'une mort de soif ou par étouffement. Ces points font encore débat alors que cela ne devrait plus être le cas : « Presque automatiquement, médecins et soignants prescrivent du liquide par voie intraveineuse et de l'oxygène par voie nasale (...) Ces deux mesures présentent deux inconvénients majeurs : elles sont inutiles et elles nuisent au patient » (voir pages 99 à 108, y compris sur l'usage de la morphine).

L'interdisciplinarité est au cœur des soins palliatifs, qui doivent inclure les compétences clés du médecin, de l'infirmière, du psychologue, du travailleur social. Dans des conditions optimales, plus de 90% des personnes en fin de vie pourraient mourir en bénéficiant d'un bon accompagnement sans avoir jamais vu un médecin spécialiste, à condition que tous les praticiens aient acquis les connaissances nécessaires. Dans plusieurs pays le chemin a été balisé par l'adoption de stratégies nationales de soins palliatifs, encore qu'il y ait « toujours un risque que des acteurs défendant des intérêts particuliers freinent le processus ». L'importance d'une assistance spirituelle est maintenant reconnue, notamment dans la définition de l'OMS des soins palliatifs. Le premier poste européen de professeur en assistance spirituelle au sein d'une Faculté de médecine a été créé en 2010 à Munich.

Le patient est au centre, bien sûr. Borasio lui donne une liste de 12 conseils pour « réussir l'entretien avec son médecin », parmi lesquels : 1. Réfléchissez si une personne de confiance devrait vous accompagner ; 6. Commencez par raconter au médecin – s'il ne vous le demande pas spontanément – ce que vous savez, pensez ou supposez déjà ; 7. Parlez de vos peurs, de vos espoirs et de vos craintes ; 8. Posez tout de suite une question si vous ne comprenez pas ; 10. Demandez au médecin d'explicitier toutes les alternatives de la stratégie thérapeutique qu'il recommande. En cas de maladie très grave, demandez-lui si un traitement exclusivement palliatif ne serait pas aussi une bonne alternative. Un chapitre parle des dispositions souhaitables pour sa fin de vie, notamment les directives anticipées.

On veut croire que, aujourd'hui, tous à la Faculté, à l'hôpital et ailleurs, reconnaissent le bien-fondé d'objectifs et de méthodes différents quand on parle de lutte contre la souffrance irréversible en fin de vie. Etant aussi rappelé que les travaux scientifiques montrent que les soins palliatifs, tout en se distançant de l'obstination thérapeutique, permettent en réalité de prolonger la vie plutôt qu'ils ne la raccourcissent – et qu'ils le font dans des conditions, en particulier de relation humaine, beaucoup meilleures. La lecture de ce livre est hautement recommandée.

Jean Martin
Membre de la Commission nationale suisse d'éthique
(2001-2013)

Jean.martin@urbanet.ch

WILL MEDICAL ETHICS SURVIVE?

I started working in medical ethics over 40 years ago. I still remember the intellectual fascination and excitement of discovering, as a clinical medical student, ethical issues that had hitherto played no part in my life. Soon after, came a sense almost of disbelief that few of the doctors training me had any interest in working through such problems. Later came partial understanding of that apparent lack of interest. For some doctors it was simply that they lacked any tools for analysing ethical issues. For rather more, it was fear that their doctor-centred view of the doctor-patient relationship might be radically altered so that they would have to practise in a different way. And that of course is what in many areas of medicine actually came about.

My fascination continued as new scientific and medical developments threw up new ethical problems – or, at least, interesting variants on previous problems. More recently, however, I find that excitement is rarely what I feel when reading the latest issue of a medical ethics journal. Boredom is more likely as article after article uses ever more powerful microscopes to examine the same old problems. Greater magnification does not often lead to greater understanding, let alone the possibility of a radically changed solution. It feels as though medical ethics has become just a job for philosophers. There is of course nothing new in that: the greatest stimulus to the development of 'bioethics' in North America in the 1970s was 90% unemployment among post-doc philosophers.

This may just be the view of a grumpy old man, but I have a genuine concern about medical ethics failing to broaden its horizons. Since I gave up publishing the *Bulletin of Medical Ethics*, I have spent much time learning about climate change. There can no longer be any rational doubt that global warming is a man-made problem that will continue to worsen. But a third of a century of scepticism by non-scientists about the science, and the resultant political inaction, has left us in a much worse place than many realise. When climate scientists talk of catastrophic climate change, the catastrophe includes a real possibility of human extinction in the next century.

Our inaction means we are now on course for a 4C temperature rise in mid-century: since the polar regions warm proportionately more, the Arctic

temperature rise will be about 10C. That is what climate scientists have feared for decades, because it will melt large areas of permafrost and release its stored methane into the atmosphere. If just 1% of the methane in permafrost were to be released in one year, it would have six times the warming effect of the carbon dioxide that man releases each year at present. Global warming would then be completely uncontrollable, with temperature rises of greater than 10C, and destruction of the ecosystems on which man depends for survival.

The fundamental problem is that there are too many human beings consuming too many natural resources too fast, with no consideration of the needs of future generations. If we are to have any chance of surviving as a race, we need to drastically reduce consumption of all sorts of things, on a very short timescale, and limit human activity to that which increases our chances of survival. In medicine, we have the paradox that the more effort and resources we put into saving individuals, the more likely it becomes that the human race will not survive. So there are many difficult issues that medical ethics practitioners could be considering and, in many cases, the groundwork has already been laid. The following are some of them:

- 1 Medical ethics has followed the zeitgeist of saying that the individual and his/her autonomy should be supreme but, if the human race is to survive, that cannot be – there can be no individual choice as to whether to work for survival or not. So how do we rebalance the needs of the individual and the many?
- 2 How do we limit medical care to what is globally sustainable?
- 3 Should we concentrate medical (and educational) effort on ensuring that children reach maturity in good condition, and leave adults to look after themselves?
- 4 Is it ethical to permit medical research looking for ways to extend life?
- 5 If people want to die, why prevent them?
- 6 Given that there are too many humans, is it ethical to permit any sort of assisted reproduction?
- 7 Pandemics are nature's way of trying to cut human numbers. Would it be more ethical to let them run their course than to try to fight them?
- 8 What do we owe to future generations?

There is a more fundamental question about the nature of medical ethics itself: how much is it a product of free-market capitalism and its domination of the modern university? Capitalism has shown that it is unable to do anything to counter global warming, being utterly short-term in its aims and careless of any consideration of the importance of 'the commons' to our survival. So human survival will depend on a rapid rejection of the capitalist model: are there enough free-thinkers, working in medical ethics and willing to break

out of its present mould, to contribute to the fight against global warming and for human survival? I really do hope so.

Richard Nicholson

bullmedeth@hotmail.co.uk

GLOBAL ADVANCE CARE PLANNING CONFERENCE FOR THE FIRST TIME IN EUROPE

The Institute of Ethics, History and Theory of Medicine in Munich is organizing a conference on advance care planning for September 9-12, 2015. Advance care planning (ACP) as a means to promote patient-centred care continues to gain increasing importance in almost all medical fields and care settings. As an ongoing, life-long communication process facilitated by skilled personnel, ACP is an innovative, effective approach eventually ensuring that when patients are no longer able to make their own medical decisions their treatment wishes are known and honoured.

The conference will be a forum for a broad audience of practitioners, researchers and policy makers from fields such as medicine, nursing, ethics, law, chaplaincy, social science and health economics. It will not only focus on end-of-life care and palliative care, but also discuss ACP in the areas of primary care, hospital care, critical care, elderly care, and others. Abstracts submission starts in September 2014. Abstracts are particularly welcome on the following themes: (1) How to implement good quality ACP, (2) patient-specific challenges; (3) ACP in different settings and (4) research on ACP.

The conference is held by the International Society of Advance Care Planning and End-of-Life Care Society (ACPEL) that was founded in 2010 in Melbourne, Australia. Its annual global conferences attract many researchers and health care professionals from around the world and aim to gain new ideas and insights on how to develop, implement and improve advance care planning. Jürgen in der Schmitt, University of Düsseldorf, and Georg Marckmann, University of Munich, will be the Scientific and Local Chairs of this conference. For more information visit: www.acpel2015.org.

Kind regards,

Ralf J. Jox
Member of the Local Organizing Committee

ralf.jox@med.lmu.de

BEING IN DIALOGUE WITH COLLEAGUES AND CLINICS ACROSS COUNTRIES

I had the good fortune to spend the month of May 2014 at the Department of Medical Humanities, VUmc at the Free University in Amsterdam. This article attests to the fertile and rewarding encounters, we as researchers can establish across national borders with other colleagues and in new clinical settings.

I have been involved in clinical ethics and philosophically based practices within health care for a number of years. The Department of Medical Humanities, VUmc matches my interests perfectly as it is known for its moral deliberation method and employing the Socratic dialogical method. The more specific reasons for my research visit were numerous: firstly, it was to learn more about the different ways of addressing the role of facilitator whether it be in a moral deliberation situation or within a Socratic dialogue; secondly, it was to spar with Dutch colleagues in regards to my Ph.D. project and work within clinical ethics additionally; thirdly, it was to gain insight into how experienced qualitative researchers stylistically address the challenge of bridging philosophy and empirical data in articles.

As a clinical ethicist at the NICU at the University Hospital Copenhagen, I have developed a structured, reflective model for health care providers to use when assessing a moral issue in the clinic. I have given it the name "the 4C model" (Knox, forthcoming) as it brings forth four central themes in moral situations: Context, consequences, concerns and conflicts. I was naturally very anxious to relate this model to the method of moral deliberation.

Simultaneously, I am working on a Ph.D. project at the University of Copenhagen, Denmark. My project is built around the intervention "The Socratic Dialogue Group" (SDG). The Socratic dialogue group (Nelson, 1949; Heckman, 1993; Gronke, 2005; 2010) is a method of dialogue that is intimately related to life experiences and abstract, critical thinking. It aims at two things: to philosophize individually and to philosophize together. The scope of my project aims to describe, investigate and analyze how a philosophical reflection in the form of a 'Socratic Dialogue Group' can contribute to dealing with rehabilitating cancer patients' ethical, existential and philosophical concerns. The participants in my project are people who are recovering from, have recovered from cancer or are chronically but not presently ill with cancer.

Several studies have testified to the need for cancer patients to talk about important life issues (Ausker et al, 2008; Nyström et al, 2007; Westman, 2006). A diagnosis such as cancer can send anyone into a state of panic, fear, and frustration. The participants in a SDG have faced daunting and intangible questions about how to address personal mortality and how to interpret the existentially and morally disruptive events that they recently lived through. Thus, cancer tends to create a great deal of existential confusion for the patient and his/her family. Our technological and clinical capabilities are creating a better prognosis for cancer patients, thus allowing them to live longer. Because of this we can expect to see an increase in the need for ways to address existential, ethical and philosophical issues. In counseling we have so far offered psychological aid and pastoral care but since philosophy is concerned with the art of living, it is relevant to consider creating constructive methods by the use of philosophy to meet the needs of cancer patients. Socratic dialogue in groups offers such a method.

My limited time at the Department served as a great personal inspiration for how to combine good methodological approaches, sound Socratic attitudes and thorough moral deliberation. I had fascinating talks with many researchers, I presented my work at a special meeting, taught a clinical ethics class and conducted a SDG. I felt very welcome and a small contributor to the ongoing scholarly discussion there. I was particularly motivated and enthused by my talks with Dr. Bert Molewijk on what information I draw out of my material, how I organize my work and particularly on strategies to improve the methodological aspect of my project. We also had thought provoking talks about how to understand the concept of "care" as one of my objectives is to develop health care services within cancer rehabilitation: What is appropriate care for patients who are finished with their medical treatment and what is provided at present? In our conversations we also contemplated how SDGs could transcend the concept of care and be read into a larger framework that touches on the moral (and maybe even democratic) importance of empowering people by means of critical thinking that enhances argumentative and decisional making skills.

Dr. Suzanne Metselaar and I conducted a fraction of a Socratic dialogue with a small group of students that turned out to be both an educational and a delightful event. We chose to focus on the part of the process where one participant recounts a lived experience that

illustrates the chosen philosophical question. A Socratic dialogue can be a trying experience as it can put you up against the wall vis-à-vis your self-perception and world view and assumptions of the human condition and human relations. I was deeply impressed by the willingness on the part of the participating students to share personal experiences and thoughts with the group. This is the first criteria for a good, beneficial Socratic dialogue.

The experience and my later very stimulating talks with Dr. Metselaar taught me that our challenges with conducting Socratic dialogue groups are similar. For example, there is the question of how to narrate a lived experience, or what is a story, and the question about how to address a story as a facilitator. Asking participants to put themselves in the shoes of the story-teller or asking them to connect with how the story is experienced by the story-teller. Participants are in the former required to reveal what they would have done if something similar had happen to them whereby you run the risk of judging or moralizing that can be detrimental to a Socratic dialogue. The latter looks for compatible experiences (Boele, 1998) that underscore the empathetic, embodied thinking of stories told among the group members. The choice between the two approaches hinges on how you want to use experience in the philosophical reflections.

Another highlight was to witness a moral case deliberation (mcd) being performed at a clinic in the VU University hospital the Department of Medical Humanities is affiliated with. Though I do not speak Dutch, I was able to detect the structure of the method and follow the different stages. Afterwards, I got a chance to discuss my impressions with the facilitator, Dr. Yolande Voskes and the health care providers who were present at the mcd. Judging from the comportment of the participants, it seemed as if they were familiar with the mcd-procedure. Dr. Voskes skillfully guided the doctors and nurses through the reflective process to discuss their position in regards to their moral dilemma. I cannot go into the actual case for reasons of confidentiality. Arguments pro (option A) and con (option B) were described and written on a flip over. The dilemma was clarified and values and norms were uncovered from the involved health care providers' perspective as well as from the patient's (assumed) perspective. Finally, they took a vote on option A and B.

One of the most apparent differences between the Dutch method of moral deliberation and my 4C model is structural and temporal. Where the former does not consist of specific questions but rather a focus on values and norms, the latter

consists of a series of general questions relevant for most ethical situations. These questions are grouped under 4 central moral themes (context, consequences, concerns and conflict). My model does not depend on going through the questions in any particular order or that all 24 questions have to be evaluated. Though the 4C model holds the possibility of being time consuming if all questions are to be addressed, it is crafted to suit the busy everyday life in a clinic. The health care providers can meander in and out of the questions that are most relevant for their case. The method of moral deliberation is more thorough going and therefore requires more time.

The thoroughness also stems from the fact that the method of moral deliberation requires a trained facilitator, where the 4C model intends to be used by health care providers who have been introduced to the model. However, the intent and outcome of both practical procedures match each other: they wish to advance reflection and understanding of moral glitches in the clinic and provide more moral transparency in the decision making process.

My mind still ponders on my experiences from Amsterdam whether it be the many talks and meetings, or the kindness of office manager Patricia Brinkman and secretary Ilze van der Berg or the several interesting conversations I had with my contact person at the Department, Dr. Elleke Landeweer. And so the dialogue continues.

Jeanette Bresson Ladegaard Knox

knox@sund.ku.dk

References

- Ausker, N et al (2008): "Danske patienter intensiverer eksistentielle tanker og religiøst liv," in Ugeskrift for Læger, 170 (21): 1828.
- Boele, D (1998): "The benefits of Socratic dialogue. Or: which results can we promise?" in Inquiry. Critical Thinking Across the Disciplines. Spring vol. XVII (3).
- Gronke, H (2005): "Socratic Dialogue or Para-Socratic Dialogue? Socratic-Oriented Dialogue as the Third Way of a Responsible Consulting and Counseling Practice," In J. P. Brune, D. Krohn (Eds.), Socratic Dialogue and Ethics. Münster: Lit Verlag.
- Gronke, H (2010): "The Different Use of Socratic Method in Therapeutic and Philosophical Dialogue," In J. P. Brune, Gronke, H., D. Krohn (Eds.), The Challenge of Dialogue. Münster: Lit Verlag.
- Heckman, G (1993): Das Socratische Gespräch. Erfahrungen in philosophischen Hochschulseminaren. Frankfurt am Main: dipa-Verlag.
- Nelson, L (1949): Socratic Method and Critical Philosophy, New York: Dover Publications Inc.
- Knox, JBL (2014): "The 4C Model: A Reflective Tool for the Analysis of Ethical Cases at the NICU, The University Hospital Copenhagen, Rigshospitalet – Denmark," in Clinical Ethics (Forthcoming).
- Nyström, M (2007): "A Patient-oriented Perspective in Existential Issues: A Theoretical Argument for Applying

Peplau's Interpersonal Relation Model in Healthcare Science and Practice," in Scandinavian Journal of Caring Sciences, 21 (2): 282-288.

Westman, B (2006): "Life, Illness and Death – Existential Reflections of a Swedish Sample of Patients who have undergone Curative Treatment for Breast or Prostatic Cancer," in European Journal of Oncology Nursing, 10 (3): 169-176.

BIOETHICS AT THE MOVIES

Cinema has always been interested in bioethical issues. Because movies are more concerned with emotions than arguments, conflicts are cinematically appealing. A movie character finds him or herself caught up in the drama of a decision-making process, and the audience finds this compelling. In a catastrophe, where not everyone can be saved, who should the doctor single out? When a patient has an incurable disease, how should the doctor break the news?

Movies often address the questions which arise at the end of life, in confrontation with dying and death. Here assisted suicide, in all its many facets, is often particularly dramatic. Not only in the movies, but also in literature, theater and music, issues surrounding the theme of assisted suicide are portrayed by bringing the persons in question so close that we are barely able to distance ourselves from them. This feeling of direct involvement makes it difficult to take a step back and make an abstract judgment. Each person is called upon to give himself up entirely to the matter in hand.

At the movies, assisted suicide is usually portrayed as a *relationship drama*. Somebody who is seriously ill asks a trusted person for help. This could be a lover (THE SEE INSIDE, Spain 2005), a spouse or girlfriend (MEIN LEBEN GEHOERT MIR, Germany 2000), a son or daughter (THE BARBARIAN INVASIONS, Canada 2003). In many cases this person also happens to be a doctor or nurse (THE ENGLISH PATIENT, USA 1998), solving the practical problem of how the assistant is to acquire the drugs or poison. The patient always utters the key paradoxical sentence which gets under the skin of each and every cinema-goer: "If you really loved me, you would help me to die!" Since movies live not from an unemotional exchange of rational arguments, but from the stirring up of strong feelings, this tangible questioning of love and friendship causes moral misgivings to become caught up in a maelstrom of confusion.

To a considerable degree, movies conduct the debate surrounding the pros and cons of active assisted suicide at a level of emotion which has to rise to great artistic challenges in order to be convincing. In the light of this drama, some viewers will inwardly hope that they are never asked to do the same thing in real life

by somebody they love. And what in movies appears primarily as an ‘act of love’ can, on closer observation, prove to be an encroaching demand or an enticement, as already employed in the Nazi movie *ICH KLAGE AN* (Germany 1941), classified to this day as a so-called “Vorbehaltsfilm” (“restricted film”). In a key scene in this movie, Hanna asks her husband, a physician, to help her to die, should her incurable disease have reached a certain stage: “Promise me, Thomas, that you will put me out of my misery when the time comes. Do it, Thomas, if you really love me, do it!” A few years later, in the French movie *MEURTES!* (France 1950), a farmer’s wife called Isabelle, who has cancer and whose pain has become unbearable, begs her religious husband Noël (played by Fernandel) to assist her in dying as a sign of his love – only straightaway afterwards to ask his forgiveness that she could request such a thing of him. Of course, 60 years ago the far-reaching possibilities provided by palliative medicine and pain therapy today clearly did not exist, and a great deal of suffering could have been alleviated if they had, and yet the intensity of the demands and the vicissitude of the emotions in this movie still affect viewers today.

Thus film – like all art forms – offers viewers the chance to broaden their own horizons. There is a recognizable common thread throughout art, with love and death always closely connected. Movies which address the theme of assisted suicide and euthanasia force us to question our own understanding of love, friendship and personal relationships. It will therefore come as no surprise that Austrian director, Michael Hanecke, gave his impressive film about euthanasia the very telling title: *AMOUR* (France/Germany/Austria 2012). Leaving us with the question: What is love? And what is friendship?

Another example: In *THE SEE INSIDE* (Spain 2005) Rosa, a single mother, tries to dissuade Ramon, a tetraplegic, from ending it all. A verbal battle unfolds about the extent of love: “And you want to hold me back against my will, is that what you call love? (*Rosa fights back the tears.*) The opposite is true... the opposite! Somebody who really loved me would help me to end my life. (*Rosa shakes her head, still fighting back the tears. Ramon is calm, his voice steady.*) That is what it means to love me, Rosa. *That is love!*”

Assisted suicide and euthanasia as the ultimate proof of love. There is hardly a movie on this subjects which does not portray a particularly dramatic understanding of love and friendship. But what for one person in love is a sacred obligation, for example assisting somebody to die because they wish it, is for another an encroaching demand, even abuse. The understanding of “true love” is ambiguous. A similar thing is true of the bonds of friendship. In movies, a request for helping to

die can strengthen relationships – but also destroy them. *One* point of the films addressing assisted suicide and euthanasia is that the protagonists are forced to clarify in a truly existential sense what friendship and love mean to them. And this is a question which cinema has never tired of discussing. We need only to think of the French director, Eric Rohmer, for example, who has allowed his film characters to exchange views about friendship and love across generational boundaries like no other.

In *CLAIRE’S KNEE* (France 1970), Jérôme, a diplomat and writer about to be married, spends his holidays alone in the French Alps, where he meets young Laura. Talking to her, Jérôme doubts whether there is any great difference between friendship and love, but does concede that friendship has something very beautiful which love usually lacks: that one friend respects the freedom of the other and does not wish to take total possession of that other. “Yes, but that is exactly what I want, I am terribly possessive!”, Laura retorts enthusiastically. “No one should be allowed to want to possess another person”, Jérôme chides Laura. If you do, you will “poison your life!” Here, too, in a completely different context, we have: a question of life and death.

What influence do these strong emotional ties have on ethical decision-making? What is required in order for an ethical reflection to succeed even in conjunction with strong personal involvement? Is a prerequisite for assisted suicide a personal relationship between the people in question? Does this have to be more than a professional relationship? Or do emotional ties romanticize the situation and make people act irresponsibly?

Gerrit Kimsma and Chalmers Clark show in their contributions that these questions, raised in movies, are not just artistic figments of imagination, but real and fundamental questions from medical practice. Examining the particular relationship structures in euthanasia cases, they refer to the phenomenon described by Kenneth Vaux in 1988, whereby some physicians who were willing to practice euthanasia on colleagues and loved ones – refused to do it on their patients! That says something about the moral nature of the act. And again: Is euthanasia a “loving act”? Is it an act of “medical friendship”?

Films, literature, paintings and music – all of these art forms underline how the ethical questions arising at the end of life have not only legal and moral dimensions, but also the power to make us scrutinize our relationships. This may be only one aspect within the complex issue of assisted suicide and euthanasia, but it is an important one, and movies enable us to remain conscious of this.

Kurt W. Schmidt
Center for Medical Ethics
Frankfurt/M.

ZEMmarkus@aol.com

RECENSION

Bernard Baertschi
L'éthique à l'écoute des neurosciences
Paris : Edition Les Belles Lettres, 2013, 250 pages.

Bernard Baertschi est maître d'enseignement et de recherche à l'Université de Genève. Il est philosophe et très engagé sur des thèmes d'éthique, en rapport avec la dignité et l'intégrité de la personne ainsi que sur les questions suscitées par les développements de la biomédecine. Le présent ouvrage est centré, à propos des apports des neurosciences, sur l'éthique normative : son but est d'examiner les normes qui dirigent notre conduite, ainsi que les valeurs qui les inspirent, en les confrontant aux connaissances nouvelles.

Après une utile introduction, notamment pour le non-spécialiste, le premier chapitre rappelle les deux approches éthiques principales, déontologiste d'une part, conséquentialiste/utilitariste d'autre part. Est discuté le dilemme éthique devenu classique du wagon fou (trolley problem) - exemple traitant des possibilités d'intervention par une tierce personne, qui peuvent entraîner la mort soit d'une, soit de cinq personnes selon la décision prise. Le chapitre 2 est une présentation fouillée du principe des actions à double effet et des situations pratiques dans lesquelles il peut s'appliquer ; enjeu dans beaucoup de débats bioéthiques, notamment en fin de vie. Discussion du choix des moyens et du moindre mal, de la place et du rôle de l'intention. S'agissant de la problématique de notre liberté d'action, entre les libertaires radicaux et les déterministes absolus/durs (qui ne croient pas au libre arbitre des individus), Baertschi propose un modèle de déterminisme doux (soft), le compatibilisme. « Le déterminisme dur demande qu'on prive de toute signification morale la différence entre crime et maladie (...) Certains auteurs militant pour l'abandon du rétributivisme au niveau pénal (...) A mon sens, les neurosciences fournissent des données qui viennent à l'appui d'un déterminisme doux, contribuant par là à sauver la responsabilité et une certaine forme de libre arbitre » (p. 97-101).

Au chapitre 3 est abordée la question complexe de savoir si, au plan philosophique et au vu de certains critères, tous les êtres humains sont des personnes: sujet aussi très présent dans les défis aujourd'hui posés à l'éthique et aux soins médicaux – ainsi que

son corollaire de savoir si seuls des humains peuvent être des personnes... Autre interrogation lourde : « Existe-t-il des êtres humains incapables de moralité ? » Thème qui préoccupe non seulement les éthiciens mais aussi la société, le système judiciaire, les experts de la santé mentale, les psychosociologues. Sont traités le grand groupe des psychopathes, l'autisme, la maladie d'Alzheimer et autres démences. « Les psychopathes ne sont peut-être pas des êtres humains à part entière, s'est demandé [le philosophe et médecin américain] Engelhardt et les expériences menées ne permettent pas vraiment de lever le doute (...) Le doute est sérieux, car être une personne est la propriété qui fonde le statut moral des êtres humains » (p. 120-121). Sont discutés les critères qui entrent en ligne de compte pour définir le statut de personne. Noter que, pour d'assez nombreux auteurs, ce qui constitue une personne est une propriété dont la possession - et la perte – est graduelle, et qu'il faudrait déterminer un seuil en deçà duquel on cesse d'en être une. (p. 150).

Puis, au chapitre 4, Baertschi présente cet aspect de la psychologie morale qu'est la réalité des tricheurs et des menteurs - et leur détection par diverses techniques quand les circonstances demandent de telles investigations. Le traitement détaillé de ces questions, y compris la prévention des comportements déviants, est suivi d'une réflexion sur l'« amélioration morale » - abordant le thème qui retient de plus en plus l'attention du renforcement (augmentation/rehaussement des capacités de l'être humain). Le titre de la conclusion interpelle : « La vérité importe-t-elle moralement ? » (avec « On doit admettre que, dans certains contextes, il existe des valeurs plus importantes que la vérité » - beau sujet).

Un ouvrage substantiel, touchant plusieurs enjeux sociétaux qu'il n'est pas/plus possible de considérer de manière simpliste, en noir et blanc ; ainsi la question du libre arbitre et celle de la responsabilité pénale ou civile. Même si les sujets sont complexes et si la lecture sera facilitée par des connaissances préalables de philosophie et psychologie, ce livre bien informé des recherches récentes se lit aisément. A recommander à celles et ceux que préoccupent les conséquences, morales notamment, des découvertes neuroscientifiques, susceptibles de modifier le regard porté sur des fondements même de nos cadres de référence, au plan médical, social et juridique en particulier.

Jean Martin

Jean.martin@urbanet.ch

RECENSION

**Maylis de Kerangal: Réparer les vivants
Editions verticales/Gallimard, 2014, 281 p.**

Maylis de Kerangal (1967) est éditrice et écrivain. Son dernier roman est l'histoire de Simon Limbres, surfeur passionné de dix-neuf ans de la région du Havre (qui est celle de l'auteure), qui arrive en coma dépassé à l'hôpital de cette ville suite à un accident de la circulation. Kerangal fait vivre ce drame de manière très vraisemblable et prenante : le vécu de l'entourage et celui des médecins et autres soignants qui l'accueillent et cherchent sans succès à le sauver. Les relations entre ces personnes, dans ce qu'on a envie d'appeler une épopée, sont marquées par le fait que Simon est un donneur d'organes potentiel.

Du côté des soignants on trouve surtout le patron du service de réanimation, une infirmière, et particulièrement l'infirmier coordinateur des prélèvements d'organes et de tissus (un des 300 de France). Dont la formation et la fonction incluent « relations aux proches, psychologie, droit, dimension collective de la démarche (...) et, autre chose de plus complexe, ce tâtonnement singulier au seuil du vivant, le questionnement sur le corps humain et ses usages, l'approche de la mort et ses représentations ». Kerangal a voulu une histoire dont tous les personnages, à quelques détails près, sont professionnellement qualifiés et compétents. On pourra trouver un peu simple, mais cela a le mérite d'être pédagogique. Les deux parents sont remarquablement dépeints dans le drame qui les assomme d'une minute à l'autre, dans leur révolte, leur déchirement, et durant les quelques heures du parcours qui les fait accepter de faire de leur fils un donneur d'organes. Noter que tout cela se déroule, de l'accident à la transplantation cardiaque à une malade receveuse dans une autre partie de la France, en l'espace de vingt-quatre heures.

« Réparer les vivants » est très bien écrit, jamais long, alternant les scènes dans divers services hospitaliers et situations médicales, dans l'appartement familial, à l'extérieur. Surtout, Kerangal est de ces auteurs qui à l'évidence effectuent un travail majeur de recherche sur le monde qu'ils investissent, ici celui des urgences/réanimation et de la médecine de transplantation (y compris les procédures et gestes de prélèvement puis transplantation des organes - ce qui est décrit, souvent en détail, est solide). Les préoccupations des professionnels de santé sont bien exposées, leur souci du patient donneur potentiel comme de son entourage, avec la volonté de respecter pleinement leurs droits et intérêts - tout en ayant à l'esprit le problème du manque d'organes et l'intérêt général, ou pour le moins celui de centaines/milliers de

personnes en attente d'organe. A noter un passage tout à fait intéressant - et amusant (p. 221-227), sur la participation de patients simulés dans la formation médicale.

Au-delà du plaisir de lire, on est enrichi. Avec des moments de poésie aussi, des trouvailles (comme de parler de « morse de la médecine » à propos des indications multiples et changeantes apparaissant sur les moniteurs) ; avec des descriptions fortes des états d'âme par lesquels passent les protagonistes de l'histoire - tempêtes personnelles et familiales. C'est un de ces livres qui, tout en étant fiction, illustrent remarquablement les diverses dimensions de questions médicales et de santé publique actuelles. Ceux qui s'intéressent à ces enjeux pratiques, psychologiques, éthiques et sociétaux seraient bien avisés de mettre ce livre à leur programme de lecture.

Jean Martin

Jean.martin@urbanet.ch

VISITING RESEARCHER AT THE ETHOX CENTRE

Entering the final stage of my PhD-project, I got the opportunity to spend one month at the Ethox Centre as a visiting scholar. My stay at the Ethox Centre gave me the inspiration and creativity needed to carry my PhD research further to a more clinical or practical level and to bring it to a favourable conclusion. My PhD-project was structured along two research lines. The first part consisted of an empirical research line that focused on the knowledge and attitudes of nursing staff toward elderly sexuality. The second part had a philosophical-ethical underpinning and aimed at investigating foundational ethical concepts and applied ethical reasoning regarding aged sexuality within elderly care in general and dementia care in particular. Upon my arrival in Oxford both parts were nearly finalized. What was still lacking, however, was a profound discussion of the overall research results and the exact relation between the empirical and the philosophical-ethical research line. Staying at the Ethox centre, attaining its weekly meetings and exchanging ideas with its members as well as the other visiting scholars allowed me to further elaborate upon the often contested relationship between empirical and normative-/philosophical-ethical research. My conversations with Michael Dunn, in particular, prodded me to think outside the box and enabled me, to a great extent, to choose my own position in the debate on how to articulate and integrate empirical data and normative reasoning in bioethics; a debate that has grown in importance since the 'empirical turn' in bioethics. Thanks to my stay at the Ethox Centre, I felt better

prepared for the final step in my PhD-project, namely the defence which took place on the 19th of May 2014.

Although the research done at the KU Leuven's Centre for Biomedical Ethics and Law proves to be quite complementary to the work done at Ethox, the Ethox Centre has its own specific strengths. Over the years, the Ethox Centre did not only invest a lot of energy in thinking about the relationship between empirical and normative research; the heterogeneity of the group and their weekly group meetings, furthermore, perfectly illustrate the inspiring close internal collaboration that characterizes the Centre. The Ethox Centre clearly has a long tradition of receiving visiting scholars. Susan Barrington, the centre's secretary, helped me making all necessary arrangements (lodging, access to the university's facilities,...) and made me feel right at home. I felt so welcome and so energized by the overall atmosphere that I spent every single working day at the office were I was assigned a desk and a computer. Everyone was very friendly, and seemed eager to chat about ethical issues. I would like to thank all members of the Ethox Centre for their hospitality and EACME for its financial support.

Lieslot Mahieu

Lieslot.Mahieu@med.kuleuven.be

MAHIEU L. (2014) Care for older people with regard to intimacy and sexuality: A clinical-ethical study with special attention to institutionalized people with dementia [Acta Biomedica Lovaniensia, nr. 640]. Leuven University Press: Leuven. ISBN 978 94 6165 123 5

DEADLINE NEXT NEWSLETTER

Deadline for the third edition of 2014:

November 15, 2014

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

Any good ideas for upcoming editions?

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

EDITORIAL BOARD

Rouven Porz, Editor

Ethics Unit
Bern University Hospital "Inselspital"
CH – 3010 BERN
SWITZERLAND
rouven.porz@insel.ch

Alessandra Bernardi

Fondazione Lanza
Via Dante, 55
35139 PADOVA
ITALY
alessandra.bernardi@ioveneto.it

Caroline Brall

Department of International Health
School for Public Health and Primary Care (CAPHRI)
Maastricht University
P.O. Box 616
6200 MD Maastricht
THE NETHERLANDS
caroline.brall@maastrichtuniversity.nl

Jean-Philippe Cobbaut

Centre d'Éthique Médicale
56, rue du Port
F-59046 LILLE Cedex
FRANCE
jean-philippe.cobbaut@icl-lille.fr

Angelique Heijnen

Maastricht University
Health, Ethics and Society
P.O. Box 616
6200 MD MAASTRICHT
THE NETHERLANDS
a.heijnen@maastrichtuniversity.nl

Jeanette Hewitt

Department of Philosophy, History & Law
School of Health Science SWANSEA
South Wales SA2 8PP
UNITED KINGDOM

j.l.hewitt@swan.ac.uk

Ralf Jox

Institute of Ethics, History and Theory of Medicine
Lessingstr. 2
D-80336 Munich
GERMANY

Ralf.Jox@med.uni-muenchen.de

Elleke Landeweer

Medical Humanities, VUmc
P.O. Box 7057
1007 MB AMSTERDAM
THE NETHERLANDS

e.landeweer@vumc.nl

Jean Martin

La Ruelle 6
CH- 1026 ECHANDENS
SWITZERLAND

jean.martin@urbanet.ch