

# EACME Newsletter

European Association of Centres of Medical Ethics

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## EDITORIAL

### Empirical Ethics Reloaded

Dear colleagues, dear friends,

I hope that this newsletter finds you all well. In this edition, we have some interesting and innovative contributions. Among others, you will find a report from France focusing on the issue of 'reproductive cloning' written by a new member of our editorial board (welcome: Jean Martin), an insight into the convincing PhD work of Joke Lemiengre, and a short introduction to a trend-setting project funded by the European Union called 'Technolife' – presented to us by Kjetil Rommetveit. In addition, Jeanette Hewitt has carefully reviewed the book 'The Ethics of Consent' and provides us with a thorough account of this work. Besides all this, it has become almost a kind of tradition that the first EACME Newsletter of each year clearly advertises the upcoming yearly conference of EACME. This year we will meet in Oslo, Norway, in September and I proudly announce that the local organisers Per Nortvedt and Reidun Forde will also introduce their centre and their work in this newsletter. And so, this brings us to the topic of this year's conference: Empirical Ethics!

Empirical Ethics? I can very well remember the first time that I heard this notion. I was confused. I thought: this is probably irony, maybe a bad joke, or maybe just a poor advertisement for an even poorer event to come. At that time, I was new to the field of bioethics, I had just started my PhD and was trained as a biologist and philosopher. So I was not immediately able to connect the word 'empirical' with 'ethics'. To me, at that time, as a biologist, the word 'empirical' referred to scientifically verifiable data, whereas 'ethics' seemed to have the very opposite meaning of that. Thus the philosopher in me softly raised his voice and started to think: "Ethics deals with moralities of human beings; morality is impregnated with implicit or explicit normativity. Well yes, maybe I can empirically measure

moral behaviour, but how could I ever be able to ground an ethics in empirical data? Can I deduct normative conclusions from empirical data? No, no way! Never!" Meanwhile the philosopher in me was not softly asking anymore, he was outraged, screaming: "If you deduct normative conclusions from empirical data then you are not an ethicist, you are a moralist! An ethicist should not be a moralist!" Or should he?

Well, enough of looking back. Now, both the philosopher and biologist in me have become at ease with the topic of empirical ethics. Moreover, I would truly call myself an advocator of empirical ethics. To me, 'empirical ethics' is still an odd notion, a strange combination of words, and one could think about improving this someday. But, despite the wording, the field of 'empirical ethics' clearly seems to possess some internal commonality. It seems that the idea of 'empirical ethics' describes some kind of basic attitude rather than a distinct field or discipline. I would even say that identifying oneself as an 'empirical ethicist' does depict a particular moral conception of oneself as a researcher and/or health care professional in the field of biomedical ethics. A baseline of this attitude would be an acknowledgement of the priority of 'practice' in the endeavour of ethics. The practical world is seriously taken into account, is analysed and studied thoroughly (I guess that is the 'empirical' part here) and then the findings are linked to normativity, ethical theories and models of morality (I guess that is the 'ethical' part in it). Of course, there is also an underlying assumption that the 'empirical ethicist' does not want to cause detriment to the practical world. The empirical ethicist rather seeks to improve practice, and possibly it is in this sense that most empirical ethicist are – consciously or not – influenced by Aristotle's theory of happiness or by his idea of 'phronesis'.

Still, it seems difficult to link 'empirical' findings to 'normative' conditions or conclusions. However, epistemologically speaking I am now less concerned with this relationship, as I have come to perceive the empirical and the normative as the opposite ends of the same sausage of interpretation (please do excuse my sloppy language here. Germans like metaphors with sausages). Nevertheless, there is something about normativity that is currently bothering me. I wonder whether all 'empirical ethicists' are aware of their own normative assumptions. So, I am not so much puzzled anymore by the relation between 'empirical' and 'normative', but rather by the moral relation that links the ethicist to his (or her) field of research.

Enough of bothering you here with half-baked reflections, but let me know what you think when we meet in Oslo. But first, do enjoy our Newsletter.

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## LETTER OF THE PRESIDENT

## LETTRE DU PRÉSIDENT

The topic of our next meeting in Oslo is empirical ethics. The past decade, empirical ethics has become one of the most debated methodological issues in bioethics. On one side of the spectrum we can find philosophers who argue that bioethics as a normative discipline cannot be reduced to empirical science. Empirical research results in facts; these facts cannot be translated into value judgments without normative premises. No matter how many physicians, nurses or patients think that physician assisted suicide is a right or a wrong way to help people who suffer unbearably and without hope for recovery, the question whether euthanasia is ethically justifiable cannot be solved by doing surveys. On the other side of the spectrum are those who claim that philosophy should be sensitive to healthcare practice. Philosophical arguments which do not take into account experiences in practice tend to become detached from what is relevant in moral life. No matter how coherent an argumentation for or against physician assisted suicide may be, if it does not take into account real life experiences of suffering and the problems which people face in dealing with them, the conclusions risk to be abstract and without prospect of helping people to develop a responsible practice.

*Le sujet de notre prochaine conférence à Oslo est l'éthique empirique. Durant les dix dernières années, l'éthique empirique est devenue une des questions méthodologiques les plus débattues en bioéthique. D'un côté du spectre, nous trouvons les philosophes qui soutiennent que la bioéthique est une discipline normative qui ne peut être réduite à une science empirique. Les recherches empiriques donnent des résultats factuels ; ces faits ne peuvent être traduits dans des jugements de valeurs sans prémisses normatives. Qu'importe le fait que beaucoup de médecins, d'infirmiers ou infirmières, de patients pensent que le suicide assisté est une bonne ou une mauvaise manière d'aider des personnes qui souffrent de manière irrémédiable, sans espoir de récupération, la question de savoir si l'euthanasie est justifiable sur le plan éthique ne peut être résolue en réalisant des enquêtes. Les arguments philosophiques qui ne prennent pas en compte les expériences de la pratique tendent à se détacher de ce qui est significatif pour la*

*vie morale. Quelle que soit la cohérence d'une argumentation pour ou contre l'assistance au suicide, si l'on ne prend pas en compte les expériences réelles de souffrance et les problèmes que les personnes rencontrent pour les gérer, les conclusions risquent d'être abstraites et de ne pas permettre d'aider les personnes à développer une pratique responsable.*

Although the debates are fierce, the positions have come closer to each other over the years. Empirical studies have become more general in the area of bioethics. Such studies have, however, not replaced theoretical analysis, but have given rise to new theoretical questions and have led to new conceptual work. Let me give you an example. Empirical research in the Netherlands shows that requests for euthanasia, next to physical suffering, often include an experiential element, such as a feeling of having lived one's life to its end, and experiencing the continuation of life as a burden. Such feelings may be a symptom for depression, but often they are realistic and understandable, giving an extra dimension to the expression of suffering and motivating the physician to take the request even more seriously. How should this element be conceptualized? By some, it is referred to as 'being finished with life'. Others have proposed to call it 'suffering from life'. These conceptualizations make a difference. The first refers to the individual making up a rational balance of his life; the second focuses on the need for help in a hopeless situation. Philosophical analysis helps to clarify these differences from a theoretical perspective, and can lead to new empirical studies, in which the results are discussed with participants in practice in order to investigate which conceptualization fits best with their experiences and can serve as a normative basis for justifying (or criticizing) aspects of their practice.

*Bien que les débats soient féroces, les positions se sont rapprochées avec les années. Les études empiriques sont devenues plus courantes dans le domaine de la bioéthique. Ces études n'ont, cependant, pas remplacé les analyses théoriques, mais elles ont donné lieu à de nouvelles questions théoriques et ont conduit à de nouveaux travaux conceptuels. Laissez-moi vous en donner un exemple. La recherche empirique aux Pays-Bas montre que les demandes d'euthanasie, suite à des souffrances physiques, incluent souvent un élément expérientiel, comme le sentiment d'avoir vécu sa vie jusqu'à sa fin, en expérimentant que la poursuite de celle-ci est vécue comme une charge. Ces sentiments peuvent être un symptôme de dépression, mais souvent ils sont vraisemblables et compréhensibles, donnant une dimension supplémentaire à l'expression de la souffrance et donnant au médecin une motivation supplémentaire à prendre la demande plus au sérieux. Comment ces éléments peuvent-ils être concep-*

*tualisés ? Selon certains, c'est à mettre en relation avec le fait « d'être en train d'en terminer avec la vie ». D'autres ont proposé de parler plutôt de « souffrir de la vie ». Ces conceptualisations font une différence. La première fait référence au fait pour l'individu de réaliser une balance rationnelle de sa vie ; la seconde se focalise sur le besoin d'aide dans une situation désespérée. L'analyse philosophique aide à clarifier ces différences d'un point de vue théorique, et peut conduire à de nouvelles études empiriques, dans lesquelles les résultats sont discutés avec les participants de manière à rechercher quelle conceptualisation correspond le mieux à leurs expériences et peut servir de base normative pour justifier (ou critiquer) certains aspects de leurs pratiques.*

This example shows that empirical research and theoretical reflection are related to one another, and need to be combined in a cyclical way. Being sensitive for the motivations and considerations of people in practice, helps us to understand what matters and can serve as a source for thought and argumentation. Theoretical reflection can help to clarify the structure of experiential tensions and provide reasons for preferring one conceptualization over another. This has also practical consequences, in that different concepts lead to different practical solutions and different normative evaluations. The concept of 'being finished with life' will focus on the balancing process of the patient, whereas the concept of 'suffering from life' will emphasize that the patient's feelings should be understandable and recognizable to the physician. Which concept is used will influence euthanasia practice in the Netherlands, and its appreciation elsewhere in Europe.

*Cet exemple montre que la recherche empirique et la réflexion théorique sont liées l'une à l'autre, et la nécessité d'être combinées dans une dynamique circulaire. Être sensible aux motivations et aux considérations des personnes impliquées dans la pratique nous aide à comprendre ce qui se passe et peut servir de base à la réflexion et à l'argumentation. La réflexion théorique peut aider à clarifier la structure des tensions issues de l'expérience et fournit des raisons pour préférer une conceptualisation à une autre. Cela a également des conséquences pratiques, en ce que différents concepts conduisent à des solutions pratiques différentes et à des évaluations pratiques différentes. Le concept d' « être en train d'en finir avec la vie » se focalisera plutôt sur le processus d'évaluation du patient, alors que le concept de « souffrir de la vie » soulignera que les sentiments du patients doivent être compréhensibles et reconnaissables par le médecin. Le concept utilisé influencera la pratique de l'euthanasie aux Pays-Bas, et son appréciation ailleurs en Europe.*

The next EACME conference will be my last one as president. Before I will leave the bureau, I will have the opportunity to participate in the debate on empirical ethics in Oslo. I hope to see you all there!

*La prochaine conférence de l'AECME sera ma dernière comme Président. Avant de quitter le bureau, j'aurai l'opportunité de participer au débat sur l'éthique empirique à Oslo. J'espère vous voir tous là-bas.*

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**ANNUAL EACME CONFERENCE 2010  
OSLO - NORWAY**

**Section for Medical Ethics – host of the annual EACME Conference 2010.**

This year the annual EACME conference will be held in Oslo, Norway. The conference will be hosted by the Section for Medical Ethics (SME), a research and educational center for ethics in medicine and health care at the Faculty of Medicine, University of Oslo, Norway.

SME was founded in 1989 on the initiative of the Norwegian Medical Association and the Norwegian Nurses Association. The Norwegian Research Council funded a 5 year research program in medical ethics from 1990 to 1995 with five PhD students. MD , PhD Reidar Lie was its first professor. Later the section was lead for many years by Professor Jan Helge Solbakk, one of this year's keynote speakers.

The section has always been interdisciplinary with students and research fellows from a variety of professional backgrounds. These backgrounds include medical doctors, nurses and other health care professionals, persons from health law and social sciences as well as theologians and philosophers. The disciplinary focus of the section spans from philosophy of medicine and basic ethical questions with relevance for medical ethics, to clinical empirical ethics, research ethics and ethics of resource allocation. Today, the section has more than fifteen PhD and post doc fellows. The research profile of the institute has always had a strong focus on biopolitics and bioethics. We have conducted 3 externally funded projects within biobanks and stemcell research. In addition, we have projects focusing on priorities within clinical practice

and nursing care, end of life decisions and the role of relatives in clinical practice as well as theoretical projects on the role of care and empathy in medicine and medical education. The number of projects within empirical ethics research has grown steadily. This is a result of SME having been given national responsibility for the development of clinical ethics committees in hospital medicine (since 2000) and for increasing the competency of ethics among employees in community health care (since 2008). The work with clinical ethics in health care is funded by The Health and Care department, and has led to the employment of several researchers since 2000. This work is especially central for the main topic of this year's conference, empirical medical ethics and clinical ethics committees.

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**QUESTIONS DE GOUVERNANCE  
INTERNATIONALE EN RAPPORT AVEC LE  
CLONAGE REPRODUCTIF**

Lors de sa 16<sup>e</sup> session tenue à Mexico en novembre 2009, le Comité international de bioéthique (CIB) de l'UNESCO a étudié le thème, toujours d'actualité, du clonage reproductif. Sur la base notamment d'une analyse de l'Université des Nations Unies (1), le CIB a rendu public en juin 2009 un rapport d'étape (2).

Y a-t-il progrès, y a-t-il besoin?

Le CIB avait invité le Professeur René Frydman, père du premier « bébé-éprouvette » français, à présenter sa position quant au clonage reproductif. L'orateur ne s'est pas appesanti sur tel ou tel thème théorique mais s'est concentré sur des aspects pratiques, de bon sens, sur la base de son expérience de la procréation médicalement assistée (PMA) - expérience clinique, scientifique et de contact avec les couples. Il a invité à poser la question de ce qu'est le/un progrès.... Interrogation de plus nécessaire. S'agissant du clonage, il y voit un non-besoin ; il n'y a à son sens aucune nécessité de chercher à obtenir des êtres humains par ce moyen. Pas de besoin d'un point de vue humain, social, sociétal. Pas non plus d'intérêt scientifique : il affirme qu'on peut répondre aux questions auxquelles travaillent les chercheurs sans utiliser la voie du clonage (y compris celles en rapport avec l'épigénèse).

Risques à considérer, physiques, psychiques, sociaux

Il a insisté sur les risques liés au clonage chez l'homme, qu'on ne peut courir comme chez des animaux. L'expérience acquise dans le clonage animal pourrait permettre de limiter les dangers pour l'homme mais il restera toujours une marge d'incertitude. A cet égard, ne pas oublier que, potentiellement dans les mêmes laboratoires et services hospitaliers, on déploie des efforts toujours plus importants afin d'assurer la naissance d'enfants sains (parfaits ?), bénéficiant d'un maximum de chances pour leur existence future. Alors, prendre les risques de développements faussés et d'anomalies par le clonage?

Il a parlé des dangers psychiques liés à l'éventualité d'être la copie (pas identique il est vrai mais très proche) d'un parent – ou faut-il dire frère/sœur ? L'être humain a de grandes capacités de résilience, sans doute. Néanmoins, s'agissant de la notion d'identité, de « soi-même », avec le clonage on avancerait en terrain quasiment inconnu (sous réserve de l'observation de jumeaux vrais - encore ces derniers ont-ils le même âge).

Etre né d'un seul parent/frère ferait le lit d'une fermeture à l'autre différent de soi. Frydman y voit le risque d'une « prison psychique ». Il relève l'importance que soit maintenu, pour chaque enfant, un espace de liberté entre ses deux parents, parents différents de lui-même. On peut rappeler la réflexion du philosophe André Comte-Sponville, s'opposant au clonage au motif que « est être humain celui qui est né de deux êtres humains ».

En général, la poussée vers le clonage participerait de la tendance à la survalorisation du soi génétique - même si ceux qui ne voient rien de problématique dans le clonage présentent les arguments de l'existence d'un bagage génétique mitochondrial et de l'importance de la culture (nurture) dans ce que devient une personne. Perspective aussi de commercialisation du vivant.

Une mesure pratique qui serait efficace

Sa vigoureuse recommandation aux bioéthiciens, politiques et législateurs est de concrétiser la seule option efficace à son sens : « interdire le transfert intra-utérin d'embryons humains obtenus par clonage ou grâce à l'induction artificielle de gamètes ». Incluant donc la référence à la possibilité, par la reprogrammation de cellules souches embryonnaires, d'obtenir des gamètes qui n'auraient aucun lien social de filiation avec une personne ayant existé. Certains, y compris dans les milieux scientifiques et philosophiques, estiment qu'on peut s'habituer à n'importe quelle origine de soi-même, aussi mal

déterminée, fumeuse, soit-elle. Mais, même s'il est parfois décrié, le principe de précaution ne devrait-il pas intervenir ici?

Nécessité d'une action internationale forte

Même en l'absence actuelle de conventions contraignantes, on doit se demander si le droit international supérieur, via la Cour internationale de justice, ne pourrait élaborer dès maintenant des arrêts prohibant le clonage, sur la base de la Déclaration universelle des droits de l'homme notamment. Cette Cour a pour but de faire observer les « principes juridiques généraux reconnus par les nations civilisées »... c'est bien de cela qu'il s'agit. Au chapitre des aspects légaux, un participant a relevé que la compétence universelle de poursuivre des infractions, même hors des frontières du pays, que connaissent des codes pénaux nationaux, notamment de Belgique et d'Espagne, pourrait être utilisée.

Le professeur français a été suivi par Thomas Faunce, médecin et juriste de la Australian National University de Canberra. Parlant d'inconscience éthique, il a mis en évidence les soucis non résolus en rapport avec l'impact à long terme d'une pratique de clonage humain sur le pool génétique en général et sur la santé publique. Il a rappelé la vulnérabilité des sujets concernés par les développements biomédicaux, soumis à des pressions multiples, et a appelé de ses vœux une action internationale déclarant le génome humain « Héritage Commun de l'Humanité » et à ce titre protégé par un instrument juridique contraignant. Dans la même perspective est souhaitée le développement d'une doctrine et d'une pratique de « biens publics mondiaux » (global public goods). Démarche indispensable aux yeux de l'auteur de ces lignes - y compris après l'échec de la Conférence mondiale sur le climat de Copenhague.

Pour terminer, les membres du CIB ont insisté sur l'urgence qu'il y a à (re)lancer une action internationale déterminée visant à mettre hors la loi le clonage reproductif.

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## DISSERTATION J. LEMIENGRE

### **“Written ethics policies on euthanasia in Flemish hospitals and nursing homes: an empirical-ethical study on development, content and impact”**

This dissertation assessed the feasibility of the written institutional ethics policy on euthanasia as a possible organizational-ethical instrument used by hospitals and nursing homes to guide their institutional responsibility in dealing with euthanasia requests of patients. The dissertation encompassed four phases in which the phenomenon of written ethics policies on euthanasia in Flemish hospitals and nursing homes was studied from several perspectives.

#### **General overview of study results**

Firstly, a systematic and exhaustive literature review was conducted to provide a general international framework to evaluate written institutional ethics policies on medical end-of-life decisions. The review showed that a written institutional ethics policy on medical end-of-life decisions is a meagerly studied phenomenon, particularly in European countries. As the majority of included studies were outdated and focused on mapping the prevalence of policies, they revealed limited information about the content of do-not-reanimate policies, and virtually nothing has been published on the impact of these kinds of policies.

Secondly, a survey was carried out to obtain a broad picture of the scope of written ethics policies on euthanasia in Flemish hospitals and nursing homes and on the extent and the way in which euthanasia policies were developed. It is remarkable that four years after enactment of the Belgian Act on Euthanasia, 63% of participating hospitals had developed a written ethics policy on euthanasia. This is in contrast to the situation in Flemish nursing homes, where euthanasia policies were developed to a much

lesser degree at the time of the survey (in 15% of nursing homes). Striking is that the policies were developed with interdisciplinary cooperation of ethics committees, care providers, and healthcare administrators and were mainly communicated to institutions' physicians and nurses.

Thirdly, a content analysis of policy documents was performed, revealing a more detailed picture of what the policies contained. The analysis revealed that euthanasia policy documents represented much more than summaries of the euthanasia law. A procedural approach was used for the analysis of dealing with euthanasia requests of patients. Generally, policies included a practical and concrete procedure to guide care providers through the euthanasia care process. To a lesser extent, euthanasia policies included a position paper that articulated the institution's stance on euthanasia. Obviously, the majority of hospitals and nursing homes narrowly applied the euthanasia law by introducing the palliative filter procedure in addition to the legal due care criteria. Next to paying obvious attention to the integration of palliative care, the euthanasia procedures also stressed interdisciplinary cooperation during the euthanasia care process.

Throughout these study phases, we identified the availability of an ethics committee, the institution's religious affiliation, and membership in Caritas Flanders (umbrella organization of all Catholic healthcare organizations in Flanders, Belgium) as contextual factors that influenced the development and content of written ethics policies on euthanasia.

Finally, a case study was conducted on the impact of a written ethics policy on euthanasia as experienced by physicians and nurses in three selected hospitals, providing an in-depth and particular perspective. The findings suggested that efforts of hospitals to develop and implement a written ethics policy on euthanasia might result in a true impact on the care practice related to patients requesting euthanasia. Overall, the euthanasia policy gave physicians and nurses a sense of being supported throughout the euthanasia care process, both in their care practice and personally. Nevertheless, the findings showed an important variation in how physicians and nurses experienced this support. The euthanasia policy mainly supported them on the practical and professional level of providing care, while its support on their ethical reflection and practice is less clear and seems to be more difficult to achieve. The findings of the case study also revealed that the presence of a guiding person—care provider who knows the euthanasia policy and the euthanasia law and who serves as a mediator that guides his or her colleagues through the different stages of the euthanasia care process—is a valuable contextual factor that augments the impact of the

euthanasia policy on physicians and nurses.

### Written institutional ethics policy on euthanasia as an organizational-ethical instrument

This dissertation and the interactions between the successive study phases enabled the development of an empirical-based organizational-ethical framework to understand the written institutional ethics policy on euthanasia as an organizational-ethical instrument to deal with euthanasia requests within hospitals and nursing homes. The study findings revealed that law, care, and ethics strongly affected the development, the content, and the impact of written institutional ethics policies on euthanasia. As such, these three cornerstones constituted the basis for the development of an empirical-based organizational-ethical framework for written institutional ethics policy on euthanasia. Furthermore, the findings of our study argued that the meaning of an ethics policy on euthanasia may vary and is bound to certain contextual factors related to three cornerstones, namely, law, care, and ethics.

We found that a written ethics policy on euthanasia does have the ability and potency to serve as an organizational-ethical instrument that guides stakeholders to deal with euthanasia requests of patients within hospitals and nursing homes. It supports healthcare institutions to take on their internal and external responsibility. However, having a euthanasia policy does not automatically lead to more internal and external transparency, more support for care providers, or more professional and ethical care practice. The study findings suggest that the development and implementation of this policy as an organizational-ethical instrument should be considered as a dynamic and gradual process, starting at the legal cornerstone, evolving to a translated caring perspective, and culminating in ethical support of care practice surrounding euthanasia questions. The empirical data indicate that this process is determined by contextual factors—such as the actual role of ethics committees, membership in Caritas Flanders, guiding persons—which could explain the varying effectiveness of different ethics policies as organizational-ethical instruments.

In this context, the major pitfall regarding the development and implementation of euthanasia policies is reductionism. Instead of considering the development and implementation of an ethical policy on euthanasia as a gradual process, institutions may reduce their ethics policy to its legal, care, or ethical cornerstone, which prevents ethics policies from becoming a comprehensive organizational-ethical instrument used to deal with euthanasia requests.

The findings of the different study phases strongly

suggest that the risk of reduction is higher for the legal and, to a certain degree, the caring or clinical aspects of euthanasia. Integrating the legal aspects of euthanasia into the ethics policy seems to be an easier assignment than its translation into clinical guidelines that support a professional care practice. In turn, the latter can be considered less complicated than incorporating incentives to explicitly reflect ethically on euthanasia and on ethical responsibility in euthanasia care processes. Consequently, optimal contextual circumstances as well as allowing sufficient time for policy development may add value to the written ethics policy on euthanasia as an organizational-ethical instrument that is used to help guide stakeholders to deal with the euthanasia requests of patients.

Joke Lemiengre, PhD in Biomedical Sciences,  
February 25, 2010

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### BOOK REVIEW

**The Ethics of Consent: Theory and Practice, Edited by Millar, F.G. and Wertheimer, A. (2010) Open University Press: New York.**

Reviewed by Jeanette Hewitt

Personal and professional morality encompasses explicit and implicit rules regarding consent, in order to protect individuals from unauthorised access to body and property and to facilitate satisfactory interpersonal relationships. This book brings together contributions considering the ethics of consent across multiple contexts in theory and practice, including medicine, bioethics, research and law.

Part one is divided into seven chapters concerned with theoretical perspectives on the nature and moral force of consent and its relationship to important ethical concepts such as autonomy and paternalism. In Chapter 1, Kleinig discusses the transformative power of consent in conferring moral authority and considers which particular factors might validate or invalidate consent, the initiator's role in shaping the nature of consent and the characteristics of immoral acts in this context. Kleinig stops short of a full discussion of the nature of acts that cannot or should not be consented

to. He is primarily concerned with the explicit signification of consent and, in a similar way to Beauchamp (who contributes a later chapter on autonomy), the necessary requirements for informed decision-making. This chapter covers familiar ground in biomedical ethical debates, and draws together widely accepted criteria for consent.

Chapter 2 is an exploration of consent in political theory and relations amongst persons. David Johnston explores the consent based ideal with reference to the ideas espoused by Kant and Mill, and argues that individual consent should also be seen in terms of wider moral obligations which may require collective action.

In Chapter 3, Tom Beauchamp summarises the autonomy and consent arguments set forth in the recently revised *Principles of Biomedical Ethics*. Here, Beauchamp states that voluntariness is the most neglected dimension of consent in medical practice and research, and that informed consent should rightly be seen in terms of the extent to which understanding and voluntariness are present. In exploring the nature of autonomy, Beauchamp focuses on acts rather than persons. He rejects what he calls the 'Split-level Theories of Autonomy' advocated by Frankfurt and Dworkin (those which rest on second-order desires and reflexivity) as being flawed in rendering many autonomous actions non-autonomous. However, Beauchamp's arguments fail to separate motivational forces from value-systems and as such, when he speaks of second-order preferences in terms of underpinning motivation, he is arguably still referring to first-order (un-reflexive) desires. Beauchamp is however clear, that he is concerned with characterising autonomous actions rather than autonomous persons and therefore his theory is developed with reference to three criteria only: intentionality, understanding and influence.

Chapter 4 by the editors, Miller and Wertheimer, changes the focus from characterisation of consenting persons to characterisation of the fairness of a bilateral transaction between consentor and the recipient of consent. Miller and Wertheimer propose a 'fair transaction view', wherein a consent transaction is morally transformative if the recipient of consent has acted in good faith towards the consentor. Somewhat controversially, the authors propose that consent may still be morally transformative in the face of deception. Claims that coercion is always incompatible with valid consent are also challenged by Miller and Wertheimer. They give the example of a prostitute (A) coerced by her pimp (C) by threats of violence into having sex for money. Where B then agrees to pay A for sex, whether or not he is aware of the coercion, the authors claim that A's consent is 'morally transformative' and B acts

fairly. This claim seems to rest on behavioural criteria only as a signifier of consent, discounting the moral relevance of free-will. Nevertheless, from a consequentialist perspective, this argument may have credibility – the consequences of B's actions certainly seem to prevent A from pain and suffering (although this was not B's motivation). If only the consequences of one's acts (even those which are unintentional) possess morality and matters of intent are irrelevant, then B's actions may be moral and A's consent morally transformative. However, indifference to the conditions under which consent is obtained is problematic in a number of contexts and seems to serve as no protection for the vulnerable or disempowered. In succeeding arguments, Miller and Wertheimer acknowledge that the morality of consent relations is in some way contextual – some forms of deception may be fair in business, but not in physician-patient encounters. Whether such difference is due to level of risk involved or the fiduciary nature of the relationship is not clear but raises interesting questions regarding the bilateral transaction view of consent for medicine. The author's claims that deception and even exploitation do not render consent invalid should however be seen through the lens of their wider discussion regarding 'fairness', which is concerned with advantages to the consentor and therefore protection of foreseeable harms.

Chapters 5 and 6 address issues of paternalism and consent. In Chapter 5, Husak discusses paternalism in criminal and medical contexts, whilst Kufflik is concerned with hypothetical consent in Chapter 6. Kufflik provides an extremely interesting analysis of the problems which arise in medical ethics when dealing with patients who have never possessed autonomous decision-making capacity and also considers the validity of advance directives in terms of their predictive accuracy for future patient wishes. In the final chapter on theoretical perspectives, Vera Bergelson then explores arguments relating to consensual and non-consensual harm, and criminal justice.

Part two examines consent in a broad range of contexts, including sexual relations, contracts, organ selling, political legitimacy, medicine and research. Chapters 8 and 9, by Alan Weirtheimer and Robin West respectively, are concerned with consent and sexual relationships. Wertheimer develops an account of morally transformative consent in law and in general morality, and considers the influences of coercion, deception, competence and intoxication. West explores claims that apparent consent to sexual relationships can be misleading, where there is failure to acknowledge harms that come from overriding the will of a weaker partner – harms caused by unwanted and unwelcome but yet fully consensual sex. These concerns with the shaping of consent and the will of

the consenters are in contrast to the functional model proposed in Chapter 4. Here, the power imbalance between consenters and recipients are seen to make the voluntariness of consent less than certain. This argument may have equal resonance for medical ethics, where the physician-patient relationship is also often characterised by such imbalance. West's discussion of consent in sexual relations therefore has a broader application to such medical contexts, where voluntariness may be as concerned with vulnerability as it is with mental capacity.

In Chapter 10, Brix explores consent in contract law and the doctrinal treatment of consent. Janet Richards then discusses consent in relation to the selling of body parts, challenging the moral force of arguments against organ-selling, which rest on best-interests and exploitation. She argues that harms arise due to lack of regulation rather than being necessarily intrinsic to organ selling itself and that legal prohibition constitutes unjust deprivation of options, rather than protection for the consenters from coercion. Where the metaphorical coercer (poverty) is not removed by legal interference, the person is left no better off by invalidation of his consent. As such, she contends that arguments against organ-selling are based on feeling rather than reasoned judgement, and benefit only those whose sensibilities are offended by an awareness of unpleasant reality. If there is a flaw in Richards' arguments, it is perhaps that she is too quick to dismiss the risks involved in major surgery and the complications of after-care, which could worsen future health or even result in death. However, since we allow persons to take such risks in altruistically donating organs to family members, the moral foundation of this line of reasoning also seems questionable. Richards' arguments then are persuasive in suggesting that the moral case against organ-selling is flawed in its assumptions about best-interests.

Chapter 12 explores the grounding of moral obligation with regard to political consent and Simmons evaluates the plausibility of classic and fundamental objections. In Chapter 13, Candilis and Lidz briefly report on advances in informed consent research. In the penultimate chapter, Joffe and Truog discuss the fiduciary character of the physician – patient relationship in terms of obligations with regard to means and ends. Miller provides the concluding chapter on consent to clinical research, and the problems which can arise due to power imbalance and therapeutic misconception.

In conclusion, it is difficult to do justice to the breadth and depth of the text in a brief review. The sheer range of subjects encompassed is worthy of note, and most chapters provide an intelligible analysis of the constituents of and limits to consent in personal and professional relationships. This is, as Miller and

Wertheimer state in the Preface, a valuable resource for readers from a variety of disciplines, and although each chapter stands alone, the insights gained from comparing consent issues in different domains are significant. The limitations of the work are perhaps that the discussion of consent relations and research are limited primarily (although not exclusively) to medical-scientific methods, with limited analysis or application to social-science methods of investigation. This is however a small complaint, and does not distract from the significance of this work.

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## THE TECHNO LIFE PROJECT

Technolife is an EU funded project under the 7<sup>th</sup> Framework Programme topic of "ethics of new and emerging technologies". It is coordinated by the University of Bergen (Centre for the study of the sciences and humanities) and has partners from Universidad Autònoma de Barcelona, University of Tartu, Manchester University, Université de Versailles Saint-Quentin-en-Yvelines, University of Copenhagen, Lancaster University, European Commission-Joint Research Centre, ISPRA.

The researchers within the Technolife project are looking for ways to turn governance and ethics of science and technology into more dialogical exercises in which citizens, communities and individuals may be heard and take part in the creation of ethical frameworks. A critical starting point is that existing approaches to ethics for governance are not sufficient for communicating ethical and political concern, and so in need of supplementary measures. The project addresses three problematic issues in existing approaches: 1) epistemologically speaking, ethics for governance often proceed on rather narrow conceptions of cognition and decision making, typically taking economic theories of rational agency as paradigmatic. Related, it is also presumed that choice is fundamentally a matter of individual decision making; 2) such (epistemological) presuppositions are embedded in institutional structures in which the framing of relevant ethical issues is left to experts; 3) it is not sufficiently taken into account that science and technology themselves make up essential elements of processes of deliberation and decision making.

This diagnosis is particularly relevant for new technologies that increasingly unfold outside of professional institutions. The project uses new technologies and media in order to promote discussion and dialogue across cultural, administrative and professional barriers. Central to the project is the establishment of an online deliberation forum used for debating ethical and political issues within three technological fields: 1) biometrics and mobility, 2) digital globes (like Google Earth) and environmental controversy and 3) enhancements of the human body through converging technologies.

Technolife develops an alternative epistemological and institutional intake. It shifts the analytical (epistemological) emphasis from cognition to imagination, assuming that imagination is central to decision making on both individual and collective levels. The concepts of imagined communities (Benedict Anderson), imaginaries (Cornelius Castoriadis) and socio-technical imaginaries (Sheila Jasanoff) are central analytical concepts deployed by the project. Imaginaries can be seen as widely shared "maps" of emerging socio-technical landscapes. Technolife will place a number of media objects in different (public) domains and use these as focal points of discussion. For each field short movies are developed and used as starting point for debate. In addition, ethical issues of the three fields are being mapped and central developments monitored. The idea here is simply that images and more emotionally laden content may better serve as triggers of debate than standard ethical principles or analysis. We develop a number of tools for that purpose, the most important being a number of short movies. Other possible "triggering objects" may include news stories, images and gadgets such as mobile phone applications.

A central part of the project deals with the development of software for online deliberation and analysis. Insights from the humanities and social sciences are used to develop the deliberative platform KerDST into a tool for discussing and analysing complex socio-technical issues on the level of imaginaries and imagined communities. The material gathered from both academic analysis and online deliberations will be analysed by leading researchers from ethics, social studies of science (STS) and philosophy. It is hoped that the ensuing results will serve to understand and represent to policy makers concerns emerging along with the three technologies studied. They will also be used for efforts to create new ethical frameworks for emerging sciences and technologies.

For more information, please visit the project website: [technolife.no](http://technolife.no). The website is presently under

construction but will be available by approximately the 15th of May.

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#### ANNOUNCEMENTS

More information about the **2010 EACME Conference "Empirical Ethics", September 16-18 2010, in Oslo** (Norway) is available at [http://www.med.uio.no/iasam/sme/seminar/eacme\\_2010/](http://www.med.uio.no/iasam/sme/seminar/eacme_2010/)

**6th International Conference on Clinical Ethics Consultation May 11-14, 2010**, Portland Art Museum, Portland, Oregon, USA.  
More information: [www.ethics2010.org](http://www.ethics2010.org)

**Workshop Moral Expertise on 28<sup>th</sup>/29<sup>th</sup> June 2010 in Cardiff, St David's Hotel**  
More details are available at: <http://shsahrcproject.swan.ac.uk/Swansea%20Conference%20Description.htm>

**Brocher Summer Academy in Global Population Health 2010**, to be held in **Geneva**, Switzerland, **12-16 July 2010**  
More details are available at: <http://www.brocher.ch/pages/programme.asp>

**International Association of Bioethics 10th World Congress of Bioethics Singapore, 2010**

The 10th World Congress of Bioethics will be held in Singapore from 28 to 31 July 2010.

More details available at:

[www.bioethics-singapore.org/wcb2010](http://www.bioethics-singapore.org/wcb2010)

**The Hastings Center Report, Call for papers submission deadline is August 15, 2010**

Essays can be sent to the editorial staff at [editorial@thehastingscenter.org](mailto:editorial@thehastingscenter.org)

**Association de Théologiens pour l'étude de la morale (ATEM) August 29 – September 1<sup>st</sup> Lyon. Healing Power: Challenge for Anthropology, Theology and Ethics.**

More information available (in French) at:

<http://ethique-atem.org/77>

**Intensive Course on Medical ethics to be held at Imperial College London, 13-17 September 2010**

Further details available at

<http://www.imperial.ac.uk/cpd/medeth>

**International academic expert seminar 'Jewish Perspectives on End-of-Life Ethics'**

22-24 November 2010, Leuven (Belgium)

More details are available at:

[http://theo.kuleuven.be/page/jewish\\_bioethics\\_programme/](http://theo.kuleuven.be/page/jewish_bioethics_programme/)

**DEADLINE NEXT NEWSLETTER**

**JULY 15, 2010**

Deadline for the third edition:  
November 15, 2010

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 editor Rouven Porz: [rouven.porz@insel.ch](mailto:rouven.porz@insel.ch)

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