

EACME Newsletter

European Association of Centres of Medical Ethics

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EDITORIAL

An Addiction To Prediction

Dear colleagues, dear friends,

As a philosopher, I quite often try to think about the very core of human beings. What does it really mean to be human? What is the most important feature of our *conditio humana*? For some time, I have thought that perhaps the core feature of human beings is not individualistic, but rather a commonality of the human race as a species, namely our cultural revolution. But then I thought, maybe the core of a human being is his or her practical wisdom, or the capability to reflect upon oneself (I know that this is pretty much linked to our cultural evolution but – dear reader – wait a second, I am just trying to build my argument).

So, what makes us human? Is it our capability to think about our own life, and to be able to decipher our own tragedies? Sometimes – especially when I am visiting my home country, good old Germany – I tend to think that the core feature of modern *homo sapiens* are their capability to permanently complain, moan and lament about what has gone wrong. But this year's soccer world cup has made me know it better. Forget about lamenting, cultural wisdom or existential reflection. The most typical core feature of our *conditio humana* is our addiction to predictions. We always want to know in advance what the future may bring. Who is going to win the game, who is going to get the cup?

The Greeks at least had a venerable oracle, or tried to read majestic eagles in the sky to find out about the possible outcome of a combat to come. And what did we have? An octopus called Paul! Do you know Paul? Did you hear of him? Paul is living in an aquarium - and I hope I don't get this wrong here as I am not an expert in predictive octopus's. Within this aquarium there are two smaller containers of glass that Paul can swim in or sit on. Before each of the soccer matches had started, one of the containers was assigned to one

team and the other container to the opposing team. Paul then got lured to the containers by some appetizing mussel snacks, obviously the same kind of food in both containers. Then he decided for either of the two containers and the team (assigned to this container) was supposed to win the upcoming match.

It is said that Paul had a probability of 80% in predicting the winning team just by choosing this or that container in his aquarium. The world cup is over now, the Spanish won and Paul did not become part of the winning teams Paella, but rather some sort of superstar of prediction, at least in Germany. And today, I read in a German newspaper that Paul is supposed to be asked about the outcome of the president's election in Russia, in two years time to come. So what do we learn from this story: Octopuses can predict the future. No, I don't think so, but: humans are addicted to prediction!

So if you – dear reader – would want to know more about your near future, I can be your Paul today. I can tell you: if you go on keeping this newsletter in your hand, you will be reading the last letter of the president of Guy Widdershoven (as the presidency of EAMCE will change in autumn), and you will find two extraordinary summaries of the PhD works of Annelien Bredenoord and Jeanette Hewitt. Besides that some book reviews, announcements and, among others, two short reports of Jean Martin.

Enjoy our newsletter, on behalf of the editorial team,

yours,

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LETTER OF THE PRESIDENT

Ethical expertise

In the past twenty-five years, medical ethicists have acquired a position in the healthcare arena. Medical ethics has become an established discipline in the medical curriculum. Research ethics committees nowadays are an obligatory passage point for clinical research. In many hospitals, clinical ethics committees make protocols and provide consultation for professionals who encounter difficult decisions, for instance concerning end-of-life issues. Medical ethicists are on the news to comment on new

technological developments in and new demands on healthcare.

These developments have changed the position as well as the identity of EACME. The number of centers for medical ethics in Europe has grown, which has led to a steady increase of members of EACME. The centers themselves have changed from small institutions with few fulltime staff-members into larger groups of researchers, including PhDs and postdocs. In order to provide a platform for these researchers, EACME conferences have developed into scientific meetings with paper presentations in parallel sessions, much like the conferences of other medical specialties.

The increasing importance of medical ethics and the development of knowledge within the field implies a specific notion of ethical expertise. It gave rise to the idea that experts in medical ethics can tell what is right or wrong based on specific knowledge and experience. Research ethics committees have the power to determine whether research is ethically permitted. Clinical ethics committees make rules and give advice on the proper course of action in a concrete case. Ethicists on the news give expert opinions about the acceptability of technological options or public demands for new treatments.

Although this view on ethical expertise has helped ethicists to acquire a position in the domain of medicine, it also has had negative consequences. The idea that ethicists as experts determine what is right or wrong, makes that researchers and physicians follow advices without reflecting on the ethical aspects of their work. They may even be tempted to act strategically in order to get permission of a research ethics committee or a clinical ethics committee, rather than act responsibly towards their patients. The expert role in the news is problematic, in that it comes along with the general skepticism concerning experts: for any expert, another one can be found who will argue for the opposite position. Again, this does not increase moral reflection and professional responsibility.

What is needed is a view on ethical expertise which gives ethicists a specific role, without making them the final judge in ethical issues. Can such a view be developed? My suggestion is to return to the classic view of the ethicist as the Socratic guide, who does not provide answers, but raises questions which stimulate reflection. This requires expertise in stimulating professionals to take seriously their own moral concerns and investigate them critically. It also requires knowledge of ethical theories and discussions, and the ability to use them, not to solve problems, but to raise questions and foster reflection. Finally, it requires openness to the possibility that people in practice may come up with ideas and

solutions which throw new light on existing theories and discussions.

These requirements are in my view also relevant for empirical ethics. We will learn more about that in the upcoming EACME conference in Oslo, and in this Newsletter, which serves as an appetizer.

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INTERVIEW S. REITER – THEIL Plenary speaker at the EACME Oslo Conference

Rouven Porz, 17th of July, 2010

Interview with Professor Stella Reiter-Theil
Director, Department of Medical and Health Ethics,
Medical Faculty, University of Basel, Switzerland

Plenary Speaker at the OSLO conference

First question:

Porz: "Could you tell us in brief something about your current academic working activities – and how these are related to the field of 'empirical ethics'?"

I am leading studies and collaborative research projects in Medical and Health Ethics where empirical material plays an important role.

In some studies we are collecting empirical data ourselves, e.g. through mixed methods approaches; one major project in Clinical Ethics is METAP to which I will refer in a presentation (parallel session) at the EACME Conference, Oslo.

In other studies, especially in large ones such as EU projects, I am accompanying the ongoing empirical research as an ethical advisor – personally or in collaboration with co-workers.

It is a two-way-relation where empirical research and ethics research interact and benefit from each other.

Second question:

Porz: "Could you give us an appreciation of 'empirical ethics' in just two sentences?"

Personally, I prefer not to use the term 'empirical ethics'. I have been supporting an active exchange between (medical) ethics on the one hand and empirical approaches on the other since more than 20 years.

As I said above, I see "Empirics" and "Ethics" in a two-way-relation, an interaction and exchange, esp. in Health Care Research.

Here, we have to take empirical material into account when we want to make substantial and relevant contributions that relate to the 'reality', e.g. of patient care. Analytic and normative thinking does not preclude, but require acknowledging empirical content.

Third question:

Porz: "I myself would depict 'empirical ethics' as a kind of basic attitude of how to do research in ethics or how to operate in the field of clinical ethics (i.e. taking real life practices into account via methods of empirical social science research). Could you please comment on my understanding of the field?"

You are giving a good example referring to "real life" as a topic of ethics research, but I am still not happy with the term 'empirical ethics'.

There can be other examples, where the empirical material that deserves being acknowledged in ethics comes from other types of empirical research – it need not necessarily be social sciences, although this is an important part of it.

Fourth question:

Porz: "Philosophically speaking, it is not trivial to deduct normative conclusions from empirical research data. Hence there seems to be a tendency that less and less empirical-ethical research studies do actually result in normative conclusions. Researchers often seem to be hesitant to touch upon issues of normativity. Still – at least in my perspective – ethics is about normativity, so my last question is: If we lose explicit normativity, does 'empirical ethics' then develop into some sort of second social science?"

I wonder, whether your assumption is valid ... that we have a lack or decline of normative conclusions in the field.

Let me emphasize that by doing or referring to empirical research in the context of (Medical) Ethics, we do not and should not "lose" the normative dimension; our task is to reflect the ethical meaning of practice, e.g. in practices of Health Care, including the data about it.

It may be perfectly appropriate to abstain from normative conclusions in certain types of studies; this depends on the objectives and the methodology.

Other studies are undertaken in order to analyse normative questions; often, this concerns the application or refinement of norms, less often the generation of norms.

In Health Care as in Life Sciences, we need more than individuals (or studies) to elaborate or develop norms; we need processes of clarification, validation, consensus-building etc. The justification of normative positions, e.g. recommendations, is receiving much interest and attention, far beyond the sphere of professional or scholarly ethicists who can hardly claim to have the (exclusive) responsibility or a privilege to

produce normative conclusions.

As a vision for the future development I anticipate a broad and interdisciplinary methodology of Medical Ethics (Research) with approaches reaching from empirical data collection over the – ethical – analysis and interpretation of empirical material to the evaluation of the ethical significance of all kinds of scientific insights that matter, to e.g. patient rights or fair resource allocation, to mention just a few examples.

Thank you, Rouven.

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INTERVIEW P. BORRY

Plenary speaker at the EACME Oslo Conference

Rouven Porz, 17th of July, 2010

Interview with Dr. Pascal Borry
Researcher at the Centre for Biomedical Ethics and
Law
K.U.Leuven - Belgium

Plenary Speaker at the OSLO conference

First question:

Porz: "Could you tell us in brief something about your current academic working activities – and how these are related to the field of 'empirical ethics'?"

My current research activities are focused on the ethical, legal and social aspects of genetics and genomics. Two important areas of my focus are the issues of genetic testing in minors and the area of direct-to-consumer genetic testing. Genetic tests have always been addressed carefully, with special attention to the release of information about the test and test results, the confidentiality of genetic information, the voluntariness of the request, the responsibility towards blood relatives and the psychological impact of the test. Careful consideration is needed when family members at risk are asymptomatic children or adolescents. Cautious reflection is needed whether and under which conditions genetic testing might be performed on asymptomatic minors. My main *research activities* in this field were oriented to investigate the ethical questions around predictive genetic testing, carrier testing and susceptibility testing in minors, and the legal position of minors in healthcare. My empirical work in this field has been focused on surveying European clinical geneticists with regard to their experiences and attitudes with regard to these issues.

With ongoing genetic discoveries and improvements in technology, more genetic tests are made available in a clinical context than ever before. Along with this increase in genetic tests, there has been a recent rise in companies providing various genetic tests directly-to-consumers, which bypass the traditional face-to-face meeting with a health care professional. Direct-to-consumer genetic tests have generated a lot of debate regarding the potential benefits and harms of this type of service. My *current research activities* are devoted to the ethical and public policy aspects of direct-to-consumer genetic testing. My empirical work in this domain has been concentrated on a questionnaire study of such companies and a questionnaire study of European clinical geneticists with regard to direct-to-consumer genetic testing.

Second question:

Porz: "Could you give us an appreciation of 'empirical ethics' in just two sentences?"

I can already start with what it is not: it should not be considered as an anti-normative approach in which the context (deduced from empirical studies) and only the context would dictate what is ethically good or evil. If that would be the case, then we are not speaking anymore of ethics. What is empirical ethics then? It should be considered as a heuristic concept which argues for the complementarity of empirical and normative approaches. This includes for example that the study of people's actual moral beliefs, intuitions, behaviour and reasoning yields information that is meaningful for normative reflection.

Third question:

Porz: "I myself would depict 'empirical ethics' as a kind of basic attitude of how to do research in ethics or how to operate in the field of clinical ethics (i.e. taking real life practices into account via methods of empirical social science research). Could you please comment on my understanding of the field?"

Bioethics is sometimes been criticized for being too abstract, too general, too speculative, and too dogmatic, as well as too far removed from clinical reality, insensitive to the peculiarities of specific situations, and unable to adequately consider the clinical contexts in which clinicians and patients are confronted with ethical problems. Empirical ethical research is one way that can help researchers in bioethics to get involved much more with their field of study and to develop a normative reflection which is not reflecting these criticisms.

Fourth question:

Porz: "Philosophically speaking, it is not trivial to deduct normative conclusions from empirical research data. Hence there seems to be a tendency that less and less empirical-ethical research studies do actually result in normative conclusions. Researchers often

seem to be hesitant to touch upon issues of normativity. Still – at least in my perspective – ethics is about normativity, so my last question is: If we lose explicit normativity, does ‘empirical ethics’ then develop into some sort of second social science?”

I don't see the goal to be to deduce normative conclusions from empirical research data. I see it as important to have a vivid dialogue between empirical research and normative reflection. If a researcher limits his study to an empirical part and does not embark into the normative reflection on his research question, then the researcher misses an important aspect of his work. But ethics is also more than normativity and the formulation of normative answers to specific questions. Ethics should be seen as the understanding of a specific moral problem, the analysis of the different arguments that support or not specific actions, and the assistance in the development of orientations, directions or eventually specific norms in this context.

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ETHICS AND MEDIA

The brutality of reality

Time magazine, in its June 14, 2010, issue, published an article entitled “The Perils of Pregnancy”, with a number of pictures about the arrival, treatment efforts and death (from uterine bleeding) of a 18 year-old mother of twins in a Sierra Leone hospital. Strong and disturbing account, I must say (though I have worked earlier in my career in deprived regions).

Four weeks later (July 12 issue), Time publishes reactions of readers. One with an uncomfortable slant: “This was one of the most shocking articles I have read (...) When I described it to a friend, I didn't mention the article was about an African. Upon realizing that the story was not actually about a Westerner, my friend was less shocked.” Another one of perplexity : “As an African woman, I fully understand the dangers women face while going through childbirth. It is horrible and terrifying. What I do not understand is why you would publish those photos”. And a third: “There are certainly better journalistic ways to bring this heartbreaking tragedy to the public eye than ‘The Perils of Pregnancy’; ways that don't use pictures that breach the basic rights of intimacy and privacy”.

Well well... In fact, the published pictures are not per se violent or even blood-soaked, and the woman in labour is not presented, in my opinion, in a way which

does not respect her dignity. The (heavy) question is : was this third reader very uncomfortable because of a possible disrespect, or because the paper brought home, in his living room, a planetary drama which indeed is a scandal ? The WHO figures about maternal mortality in the world have hardly diminished over the last two decades: half of a million deaths a year, 1'400 a day, one every minute... The most disturbing aspect of the problem being that, in principle, most of these deaths could be prevented by rather simple and cheap means. No statistical ratio represents more forcefully than maternal mortality the health care gap between developing and industrialized countries.

Certainly there are limits to what journals should - or should not - publish. But it might be too simple to criticize editors and journalists while or because one has difficulty in facing an unacceptable state of affairs.

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THESIS J. HEWITT

Rational Suicide in Schizophrenia

The topic of rational suicide has come increasingly to the fore in public debate in Britain. Philosophical literature provides diverse perspectives on the moral legitimacy of claims regarding the rationality of suicidality, but frequently voices a homogeneous view when it comes to the question of the rationality of suicides of people with serious mental illness. As someone with a background in mental health nursing, I am often struck by the widely held (and arguably inaccurate) notion that a diagnosis of serious mental illness ipso facto denotes a state of global irrationality. A number of injustices can and do arise from this belief, the most serious of which relate to the loss of sovereignty over self. The idea that people with serious mental illness suffer injustice in relation to autonomy rights seems particularly glaring in relation to suicide, where the ultimate sovereignty over self is denied without further qualification other than the person's diagnostic label. It was this taken for granted assumption that provided the impetus for me to analyse the concept of rational suicide for people with schizophrenia in philosophical and biomedical literature for my Doctoral thesis. What follows below is an attempt to summarise my study and in particular the main conclusions which I drew about the rationality of suicide for people with schizophrenia.

Psychogenic pain rarely qualifies as acceptable grounds for rational suicide. People with schizophrenia who voice suicidal ideation are usually deemed irrational in their desires by both psychiatric and philosophical paradigms, wherein their desire to die is seen to arise as a direct consequence of mental disorder. This construction of suicide and schizophrenia however fails to take account of two key variables: Firstly, the risk of suicide for people with schizophrenia has been shown to be highest when positive symptoms are in remission and/or where insight is greatest. Secondly, quality of life studies show that subjective satisfaction is substantially related to social functioning and not the severity of positive symptoms. Such data questions the assumption that suicidal ideation for people with schizophrenia is always a direct result of psychotic phenomena.

People with a diagnostic label of schizophrenia are frequently labelled as irrational by virtue of the status of their disorder. This has led to a lack of acknowledgement of the view that the features of psychosis, i.e. delusions and hallucinations, are distinct in their focus and do not affect overall capacity for rational autonomy. The presence of delusions and hallucinations does not however inevitably lead to widespread confusion in same way as organic delirium does - thought disorder does not invariably encompass all cognition, emotion and volition; a person with schizophrenia, even in the most acute phase of illness may still possess autonomy with regard to some matters if not to all. Mental capacity assessment in psychiatry is however concerned with patients' ability (or willingness) to understand and assent to their diagnostic label and treatment, commonly known as 'insight.' Failure to comply with treatment is seen to be a lack of insight into the presence of a mental disorder and thus a sign of irrationality. Such a narrow conception of rationality does not seek to assess whether a person is able to reasonably appraise their quality of life or realistically appreciate and mourn the intra-psychic and interpersonal losses which have resulted from living with psychosis.

The presence of psychotic symptoms does not necessarily preclude a person from possessing a capacity for second-order desires and in possessing such desires, the ownership of a value system. Schizophrenia leads to impairments in many aspects of life, including physical and cognitive functioning, mood state, social and occupational roles, and economic stability, resulting in consequent psychic, social and interpersonal losses. Such a person may sincerely regret these losses which mean that he or she is no longer able to live in accordance with a value system that esteems psychic, social and interpersonal functioning. The multiple losses associated with living

with schizophrenia may lead to a state of chronic demoralisation or existential hopelessness, which is not pathological, but a rational response to having to live with a chronic and relapsing disorder. Such prolonged psychological suffering may legitimately influence a person's desire to die and may lead to circumstances where the suicides of people with schizophrenia can be correctly viewed as rational. Where a person with schizophrenia possesses a logical belief system with regard to the ending of suffering, I conceive of the desire for death in this circumstance as a higher-level want or second-order desire, where the goal to minimise harm and/or suffering cannot be met in any other way.

Coercive suicide intervention for people with schizophrenia may therefore be strongly rather than weakly paternalistic in the kind of circumstances I have outlined. It seems logically consistent to agree that persons with schizophrenia who suicide due to certain delusional beliefs (e.g. nihilistic), or as the direct consequence of command hallucinations, are not autonomous with regard to suicide. However, I contend that it is equally possible to have delusional beliefs and hallucinations, still be able to reflect on the value of one's life due to these psychotic phenomena, and autonomously choose to die, where such a person's desire to die results from despair, rather than delusion. Moral justification for suicide intervention is therefore not a simple matter of preventing harm, for what constitutes the greatest harm for the person depends on whether death can be conceived of as a greater harm than continued suffering.

The moral argument supporting a terminally ill person's right to die is sometimes founded on the principle of mercy (Rachels, 1986; Battin, 1994). This principle obligates a moral agent not to prolong the pain and suffering of another, where this is in accordance with the person's wishes. In some circumstances, this means that it might be merciful not to intervene to prevent the suicides of others, where the continuance of life will lead to enduring pain and suffering. If a person with schizophrenia considers that it may be more harmful to continue living with the experience of serious mental illness, for overall he or she endures less harm or suffering through dying, than by continuing to live with a distressing illness, then the principle of mercy may demand that we refrain from interfering with their act of suicide.

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ETHIQUE DANS UN MONDE CUPIDE

En mai dernier, j'ai participé à un fort intéressant séminaire de l'Espace éthique de l'Assistance publique-Hôpitaux de Paris. Cet Espace, créé en 1995 et dirigé par Emmanuel Hirsch, a une importante activité de formation et de publication. J'évoque notamment un exposé de Elisabeth Sledziewski, philosophe et politologue de l'Université de Strasbourg. La politique au sens large - la vie dans la Cité - est en déficit de sens, dit-elle. Or le sens ne tombe pas du ciel, il se construit et nous n'en avons pas de « réserves », dans un monde qui a lâché les principaux repères qui lui servaient jusqu'ici... Entropie du sens ?

Elle a fait référence au Prix Nobel d'économie 2001, Joseph Stiglitz, critique fort des évolutions récentes au plan économique et financier ; voir son dernier livre *Freefall*, en français *Le triomphe de la cupidité* (1). Aujourd'hui, notre monde fonctionne à l'avidité. Temps de crépuscule du devoir (Gilles Lipovetsky) et du « Moi-Soleil ». Les intérêts sectoriels sont les seuls qui comptent, on est dans *The Tragedy of the Commons*, selon le titre prophétique de Garrett Hardin en 1968. A propos des espoirs suscités par l'élection du président Obama, cette formule d'un observateur : « Il n'a que légèrement redispesé les fauteuils sur le pont du Titanic »... La crise morale se répercute dans tous les domaines de la société, système de santé compris

Réponse inadéquate et bureaucratique à cette perte de sens et de considération de l'intérêt général, l'emballement législatif ; faute de valeurs on promulgue des lois. Alors que - Montesquieu dixit - il convient de « garder à la loi sa rareté et sa majesté », on légifère tant et plus ; la loi devenant ainsi de plus en plus pointilliste, contingente.

La reconquête du sens passe par la reconnaissance

de l'autre et l'ouverture à lui, a insisté Elisabeth S. Il importe de reconnaître sa dette vis-à-vis du prochain (rapports personnels, rapports professionnels entre soignant et soigné), de la Cité (citoyenneté) et de l'humanité tout entière. Toute éthique est contractuelle, co-produite, lien à l'autre.

Référence:

1. Stiglitz J.E. *Freefall. En français : Le triomphe de la cupidité. Paris : Ed. Les liens qui libèrent, 2010.*

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THESIS A. BREDENOORD

Ethics at the interface of reproductive medicine and genetic technology: the case of mitochondrial disorders.

Introduction

From 2005 until 2009, I have been a PhD-fellow at Maastricht University, department of Health, Ethics & Society. My PhD thesis is based on the workpackage Ethics of the EU 6th Framework Program MITOCIRCLE: "Mitochondrial disease: from bedside to genome to bedside", which I conducted under the supervision of prof dr Guido de Wert, prof dr Guido Pennings and dr Wybo Dondorp.

Whereas assisted reproductive technology (ART) was initially used for infertility problems, it has increasingly been deployed as a vehicle for genetic technology. In my thesis I examine the ethical issues that arise when reproductive genetic technology is used to prevent the transmission of mitochondrial disorders, particularly those caused by a mutation in the mitochondrial DNA (mtDNA).

When people talk about genes, they usually refer to the nuclear genome. All human cells, however, contain two different genomes. One indeed is located in the nucleus and follows a Mendelian pattern of autosomal recessive, dominant or X-linked inheritance. This genome is by far the largest, containing about 22.000 genes. The other genome is located in the mitochondria. These are tiny organelles, which exist outside the nucleus, in the cytoplasm. They serve as the 'batteries' or 'powerhouses' of the cell. The mitochondrial genome is extremely small, containing 37 genes, but defects in the mtDNA can lead to a wide

variety of usually severe disorders. One in 400 people has a maternally inherited, mtDNA disease mutation, causing a range of illnesses, including deafness, blindness, diabetes, loss of skills, heart and liver failure.

There are no treatments available to cure these disorders. Therefore, helping carriers of mitochondrial mutations to have healthy children, free of mtDNA disease, has been a central focus of attention. In my thesis I ethically evaluate various reproductive genetic technologies used with the aim of preventing the transmission of mtDNA disease.

Prenatal diagnosis

A first reproductive option for carriers of mtDNA mutations regards prenatal diagnosis, in which the fetus is tested early in pregnancy, possibly followed by a termination. Due to the characteristics of mtDNA genetics, offering prenatal diagnosis could be technically and ethically challenging. The mtDNA is inherited via the female line only and many mtDNA mutations are heteroplasmic. This means that there is a mixture of normal and mutant mtDNA in one person. If the mutant load, i.e. the ratio of mutant to normal mtDNA, exceeds a specific threshold, clinical features become manifest. However, for many mutations the threshold to disease expression is not known. Although the disease will be most severe in people with the highest proportions of mutant mtDNA, this proportion varies from one generation to the next and cannot be predicted.

These characteristics of the mtDNA make it difficult to estimate recurrence risks for a couple and if one decides to conduct prenatal diagnosis, it is often difficult to interpret the test results and to predict the health of the child. A limited number of mtDNA mutations allow reliable predictions, though results in the 'grey zone' are problematic. This results in a wide array of ethical questions: is it morally acceptable to offer prenatal diagnosis when the test result may be difficult to interpret? What about the psychological and moral consequences of terminating a pregnancy based on ambivalent data? I have reviewed these and other questions and conclude that although prenatal diagnosis is an acceptable reproductive option for most mtDNA mutations, other reproductive strategies may in some circumstances be morally preferable.

Preimplantation genetic diagnosis (PGD)

A second reproductive option concerns PGD, in which embryos created by means of in vitro fertilization (IVF) are analysed for a particular genetic mutation. After the genetic analysis, one or two unaffected embryos are transferred to the womb. Traditional applications of PGD are targeted at Mendelian and chromosomal disorders. In those cases, it is in principle certain

whether the relevant gene defect is present and which of the available embryos can safely be transferred. In case of PGD for mtDNA disorders, this is less clear. It is conceivable that in some cycles only affected embryos (with a certain mutant load) are available for transfer. So instead of 'promising' parents a healthy child, PGD in these cases can only aim at reducing reproductive risk. From an ethical point of view, such a 'risk-reducing' PGD raises challenging questions about parental and medical responsibilities. The main argument in favour of PGD for mtDNA disorders is that it offers couples at risk the opportunity of reducing their chances of having a severely affected child. Another important argument in favour of PGD concerns reproductive autonomy. This is usually defined as the right to control one's own procreation unless there is a compelling reason for denying a person that control. The rationale behind this principle is that in a liberal democratic society, the presumption is that people should be free to make their own choices according to their own values.

There are many possible arguments against such a 'risk-reducing' PGD. For example, one could argue that the transfer of an embryo at risk is at odds with the welfare of the future child. We defend the reasonable welfare standard: (medically assisted) reproduction is morally acceptable as long as the resulting child has a reasonable chance of an acceptable quality of life; a high risk of serious harm would be the contra-indication. From this perspective, the transfer of an embryo at risk may be justifiable as long as the child will not run a high risk of serious harm. Another possible objection to PGD for mtDNA disorders is that such an application of PGD is too complex for parents to decide. Also our empirical studies, in which we conducted in-depth interviews with patients and professionals, show that many professionals consider mitochondrial genetics a 'test case for reproductive autonomy'. Professionals struggle with the handling of ambiguous data often linked to PGD (and prenatal diagnosis) for mtDNA disorders, and all feel that the inherent challenges of reproductive genetic testing and counseling are intensified in the context of mtDNA disorders.

Although potential objections are manifold, none of them supplies convincing moral arguments to regard risk-reducing PGD as unacceptable. Nevertheless, introducing this new application of PGD in clinical practice will raise further complex issues of determining conditions for its responsible use. Therefore, we elaborate which conditions should be met in order to justifiably introduce PGD for mtDNA disorders in clinical practice. One of the conditions for example is that it should be made clear whether PGD is sufficiently reliable. It is important to ascertain that the cell(s) taken for analysis adequately represent the composition of the embryo as a whole. Another condition is that an appropriate cut-off point (i.e. the

threshold of mutant load above which no embryos are considered for transfer) is determined beforehand. In addition, the medical team could offer to preferentially transfer male embryos, as men do not pass on the mtDNA mutation to the next generation. Such a 'transgenerational' sex selection has the twofold aim of avoiding difficult reproductive decisions for the future child and avoiding transmission of the mutation to a possible third generation.

Ooplasmic transfer

In theory, ooplasmic transfer could be a third reproductive option for carriers of mtDNA mutations. In reality, ooplasmic transfer is not proven safe and effective. It encompasses the transfer (or injection) of donor ooplasm with normal mitochondria to the oocyte of a woman who carries mutant mtDNA in her oocytes. It has been developed as a fertility technique for women experiencing repeated embryonic development failure and was heavily criticized for its premature introduction. In these initial applications, only small amounts of donor ooplasm were transferred to the recipient's oocyte. To prevent the transmission of mtDNA disease, a much larger amount of donor ooplasm would be needed. It is seriously questioned whether it is possible to introduce such an amount of donor ooplasm into the oocyte. As long as ooplasmic transfer is not proven safe and effective as a reproductive option for carriers of mtDNA mutations, clinically offering ooplasmic transfer would be both futile and unethical.

Nuclear transfer

A fourth reproductive option for carriers of mtDNA mutation could be mitochondrial gene replacement by means of nuclear transfer. Although nuclear transfer has not been offered to patients yet, a first-in-human application may simply be a matter of time (in view of recent technical successes in laboratories in the USA and the UK). A clinical application would involve the transfer of the nuclear DNA of a woman carrying an mtDNA mutation into an enucleated donor oocyte. This should result in healthy offspring carrying the mtDNA of the oocyte donor and the nuclear genome of the prospective parents. The nuclear transplantation can be performed before and after IVF, using the nucleus of an unfertilized oocyte, the pronuclei of the zygote or the nucleus of a blastomere of an embryo.

Nuclear transfer raises a wide array of both conceptual and ethical questions. First, we discuss whether nuclear transfer for mtDNA disease entails germ-line modification. The mitochondrial genome differs in many aspects from the nuclear genome: first, the mitochondrial genome contains only a tiny amount of the total amount of DNA; second, it has a very specific function (providing the cell's energy metabolism); third,

it has its own transmission pattern. However, the distinctive feature of germ-line modification is that the genetic modification can be transmitted to further generations. Therefore, there is no good reason for not also applying the concept of germ-line modification to modification of the mitochondrial genome. Second, we discuss whether nuclear transfer entails reproductive cloning. The answer to this question also depends on which definition of cloning one deploys. One variant of nuclear transfer, in which the nucleus of a blastomere (one cell of the early embryo) is transferred to an enucleated oocyte, may indeed amount to reproductive cloning. More in particular, it may amount to reproductive embryo cloning.

After having scrutinized the above conceptual questions, we examine the validity of the main categorical (non-safety) arguments used against germ-line modification and reproductive cloning. Opponents have for instance argued that germ-line modification and reproductive cloning are repugnant and unnatural, or that they violate human dignity. Others have argued that germ-line modification would violate the child's right to an open future. This means a right to have one's future options kept open until one is capable of making one's own decisions. The moot point of the argument is the fear that it would become possible to alter presumed 'essential characteristics' of the make-up of future generations. For this reason, germ-line modification of the nuclear DNA has led to more ethical controversy than modification of the mtDNA. We challenge the assumption that modification of the mtDNA is ethically less problematic than modification of the nuclear DNA because the first would not involve the possibility of altering essential characteristics. Even if mtDNA has only a basic cellular function, then it is still meaningful to say that germ-line modification of the mtDNA is likely to change the identity of the future person. However, even if nuclear transfer may alter the identity of the child, then a clinical application of nuclear transfer to prevent mtDNA disease, so we argue, could still be compatible with the position that one should not violate the child's right to an open future. We conclude that were nuclear transfer for mtDNA disease to become safe and effective, dismissing it because it involves germ-line modification and possibly also reproductive cloning is unjustified.

Conclusion

All strategies, with the exception of ooplasmic transfer, could potentially serve as acceptable reproductive options for couples at risk of transmitting an mtDNA mutation to their future offspring. With regard to prenatal diagnosis, PGD and nuclear transfer, the adjective 'potentially' is used to indicate that none of these strategies is unconditionally acceptable. All reproductive options ask for a further filling in: whereas prenatal diagnosis and PGD require further

qualifications for a responsible use in clinical practice, nuclear transfer requires further preclinical research before a clinical application could be appropriate (and the ethics of a first-in-human application of nuclear transfer for mtDNA disorders asks for further debate as well). Having to reproduce by means of one of the reproductive interventions as described in this thesis is, in some way, a tragic situation as all interventions offer some serious moral disadvantages. If, or as long as, not one strategy clearly towers above the others, it seems reasonable to allow the couple to prioritise and balance the pros and cons of the available interventions according to their own values. Of course, this is not without any qualifications. After all, the moral minimum as defended in my thesis regards the avoidance of a high risk of serious harm for the child, added with continuous efforts to reduce these risks as much as reasonably possible.

People interested in receiving a thesis can send an email to: A.L.Bredenoord@umcutrecht.nl

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BOOK REVIEW

Review of the book „Cutting through the surface. Philosophical approaches to bioethics“, by Tuija Takala, Peter Herissone-Kelly, and Sören Holm.¹

¹ This review is (in parts) a re-print version of the one published by R. Porz in *Medicine Health Care and Philosophy*, n° 4, 2010.
Thanks to Roberto Adorno.

Reviewed by Rouven Porz

This marvellous volume is about the philosophical side of bioethics, and it clearly argues for philosophical reflection in the field of bioethics. As S.K. Hellsten puts it in her text: "...today we can detect two main polarized ways of doing "bioethics": abstract theoretical speculation detached from reality on the one hand, and political pragmatism on the other. In order to build a bridge between these extremes, there is a need to bring reflection and argumentation back to bioethics" (p. 17). The discipline of philosophy can bring back this reflection, it can help to dig deeper, and can help to "cut through the surface" as the title of the book indicates. Let me give you a very brief overview: In a truly philosophical manner, the book starts with three chapters that tackle precisely these kinds of introductory issues by asking the question "What is bioethics and where should it be going?" (we talk about the authors S.K. Hellster, S.O. Hansson and H. Lesser

here). The following chapters then investigate some core issues in methodology, and how to proceed in bioethics from different viewpoints (V. Launis, J. Räkka, P. Louhiala and L. Toiviainen). We then move on to a block of chapters that deal with the concepts of dignity (S. Woods), autonomy (N. Scott), precaution (M. Parker and P. Vineis) and solidarity (V. Arnason). Finally, Sören Holm ends this row of chapters by eloquently addressing a potential future problem for us all (innocently wrapped up in a lyric of the Beatles): "Will you still need me, will you still feed me, when I am 64?" Section four of the book focuses widely but quite provocatively on medical research and eradicating human diseases (M. Battin et al., J. Harris and R. Rhodes). What follows in section five is a special collection of chapters in the area of reproductive medicine that build on some provoking arguments of Häyry. He once showed that one could argue that human procreation is "irrational" and even "immoral" – there are remarkable responses and intriguing ideas in this book in reply to this challenging contention (F. Ruokonen and S. Vehmas, F. Leavitt, R. Ashcroft, R. Bennett and T. Buller). The book ends nicely with some philosophical responses to the debate around the field of enhancement (written by L. Bortolotti, H.A. Gylling and T. Aikraksinen).

Let me conclude my brief review like this: if the field of bioethics was music, then this book would certainly be rock'n'roll. It certainly rocks and it is rebellious. That was my very first impression after I had read the foreword by M. Häyry, and it was my very last thought, after having been convinced by T. Airaksinen that we are all moving towards a future of cyborg-societies. In this book, all 23 texts perfectly fit together, nicely arranged, you, as a reader, feel as if you were part of the discussion, part of a late-night birthday party with friends that share the same interest. And talking about birthday parties, the editors state in their preface that this wonderful collection is a book to celebrate Matti Häyry's 50th birthday. And even if you are new to the party, new to the field of bioethics, you truly learn a lot, as all the authors take their time to thoroughly ground their ideas and arguments in an impressively coherent style. It is this coherent style that distinguishes this book from other loosely edited volumes.

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INNOVATION IN TEACHING, LEARNING AND ASSESSMENT OF MEDICAL ETHICS AND LAW

In September 2007 I presented a paper on Teaching, Learning and Assessment of Medical Ethics and Law in UK Medical Schools at the EACME conference in Zurich. This described a programme initiated by the Institute for Medical Ethics (www.instituteofmedicalethics.org) with the overall strategic objective of promoting and facilitating best practice in teaching, learning and assessment of medical ethics and law in UK medical schools.

The first specific objective was to reassess and update the core curriculum for medical ethics and law. This has now been published [Stirrat GM, Johnston C, Gillon R, Boyd K. Medical ethics and law for doctors of tomorrow: the 1998 consensus statement updated. *J Med Ethics* 2010;36:55-60] and can be accessed at <http://jme.bmj.com/content/36/1/55.full.html>.

Work on the other objectives continues. These are:

- Development and dissemination of learning resources.
- Drawing on developments in technology-supported learning to facilitate the exchange of resources among schools.
- Facilitating the training of 'non-expert' teachers
- Provision of clear, practical but broad guidance on the purposes and methods of formative and summative assessment.
- Setting an agenda for the development of a national standards-based resource base of valid and reliable assessment tools.
- Developing assessor training with the HEA and other interested parties.

As part of this programme the IME is holding its Fifth Conference on Medical Ethics and Law with the title - Innovation in Teaching, Learning and Assessment of Medical Ethics and Law. It is being held on Friday 4 February 2011 in BMA House, Tavistock Square, London.

Further information can be obtained from Professor Gordon Stirrat: g.m.stirrat@bristol.ac.uk

Senior Research Fellow at the Centre for Ethics in Medicine – Bristol, UNITED KINGDOM

ANNOUNCEMENTS

The annual EACME Conference "Empirical Ethics", is fast approaching. The Conference, held in Oslo from the 16th-18th of September, promises to be

very interesting. There will be four Keynote presentations, 80 abstract presentations and posters. A reminder that the deadline for submitting an abstract for poster presentation is August 15th, 2010. For more information go to http://www.med.uio.no/iasam/sme/seminar/eacme_2010/index.html or contact post-sme@samfunnsmed.uio.no Please put EACME in the subject line. We look forward seeing you all in September.

Applications are invited for entry for the 2010-11 MA in Bioethics and Medical Law at St Mary's University College, London. TW1 4SX.

The course can be taken part-time over three years or full-time over one year, on site or by distance learning. Overseas applicants are welcomed.

The programme is taught by a multi-disciplinary team of doctors, lawyers, philosophers and theologians based at the Centre for Bioethics and Emerging Technologies within the School of Theology, Philosophy and History at St Mary's University College. Full details of the course and application forms are available on www.smuc.ac.uk/postgraduate/bioethics/index.htm

Applications are accepted until Sept 13th 2010 and should be sent to the programme director, Dr Trevor Stammers at stammerst@smuc.ac.uk

Association de Théologiens pour l'étude de la morale (ATEM) August 29 – September 1st 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>

Ethik in einer alternden Welt' to be held in Heringdorf, Germany, 23-26 September 2010.

For more information: <http://ethics-morals.com/>

Conference 'Gender and Health: Crossroads and Potentials' Linköping, Sweden, 27-29 September 2010

For further information please visit the website: http://www.imh.liu.se/avd_halsa_samhalle/genderandhealth?l=en

Postgraduate programmes in Health Care Ethics and Law are offered at the centre for Ethics in Medicine at Bristol University.

For further information please visit the website: <http://www.bristol.ac.uk/ethicsinmedicine/>

Postgraduate Medical Ethics courses are offered at Keele University.

For more information, please visit the website:
<http://www.keele.ac.uk/ethics>

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/

Human Medical Research: ethical, economical and socio-cultural aspects

Interdisciplinary conference, 07th – 11th February 2011, Ruhr-University Bochum, Germany.

Call for abstracts containing a brief outline of the presentation (1 page) and a **Curriculum Vitae** till 07th November 2010 by email to.: verena.sandow@rub.de

For more information: <http://www.rub.de/malakow>

4th International Congress on Bioethics 'The Autumn of Life: Ethical Challenges of Aging', Strasbourg, March 23-26th, 2011

For more information:

[http://ethique-alsace.unistra.fr/index.php?id=4666&no_cache=1&tx_ttnews\[tt_news\]=2459&tx_ttnews\[backPid\]=4559](http://ethique-alsace.unistra.fr/index.php?id=4666&no_cache=1&tx_ttnews[tt_news]=2459&tx_ttnews[backPid]=4559)

ICCEC Conference on Clinical Ethics and Consultation to be held at the VU university medical center, Amsterdam, The Netherlands, May, 18-21, 2011

For more information: <http://www.iccec2011.org/>

CFP: Moral Responsibility: Analytic Approaches, Substantive Accounts and Case Studies. International Conference, Center for Ethics & Value Inquiry (Ghent University, Belgium) Monday and Tuesday 18-19 October 2010

For more information visit the conference website at:

<http://www.cevi-globaethics.ugent.be/MR2010>

DEADLINE NEXT NEWSLETTER

Deadline for the last edition of this year:

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:
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