

**29th EUROPEAN CONFERENCE
ON PHILOSOPHY OF MEDICINE AND HEALTH CARE
19 – 22 August, 2015**

VENUE:
THAGASTE
ACADEMIESTRAAT 1
9000 GHENT

"Medicalization"

Organised by:
The European Society for Philosophy of Medicine and Healthcare
(ESPMH) and the Bioethics Institute Ghent, Belgium

ABSTRACTS

Mind the (Cartesian) gap: discourse analysis of subjective and objective experiences of the body in manual therapy

Abbey, Hilary

H.Abbey@bso.ac.uk

Background: Chronic pain is a complex healthcare problem that impacts on patients' experiences of 'body as object' and of their 'lived body'. Biomedical treatments often fail to address individual distress but it is unclear if or how, bio-psychosocial approaches differ. 'Patient-centred' therapists aim to bridge the mind-body gap through 'holistic' interventions but it is not known how this is enacted, or what impact it has on patients' awareness and function. The concept of embodiment developed by Merleau-Ponty and research into embodied cognition suggest there may be under-explored opportunities to work in more philosophically integrated ways that acknowledge the inseparability of mind and body experiences.

Design: This paper presents an analysis of philosophical discourses about the ontological nature of the body and dysfunction, and epistemological beliefs about how pain can be explained and managed. These discourses were co-constructed during manual therapy interactions between an osteopath and four patients attending an innovative chronic pain management course. The course integrated Mindfulness and Acceptance and Commitment Therapy based interventions into osteopathic treatment for individual patients. It aimed to enhance body awareness, promote flexible psychological responses to discomfort, and develop self-care skills. The study formed part of a Professional Doctorate degree and data was collected from audiotapes of individual pre-course interviews and six treatment sessions. Discourse Analysis was used to explore the context of medical discourse within which interactions took place, followed by Micro-Discourse Analysis of key interactions to explore the dynamic processes by which meaning and action were co-constructed.

Results: Course aims were to promote learning by focusing on patients' awareness of cognitive, affective and bodily experiences during physical treatments. The therapists' stance was that patients were 'experts' in their own life experiences but data analysis indicated that conversations rarely focused on present moment patient awareness and both participants tended to default to a 'practitioner as expert' relationship. Occasionally, both participants focused on 'here and now' experiences and changes in discourse indicated that this made space for a more embodied sense of awareness. The practitioner moved between giving 'expert' biomedical explanations and providing a safe, tactile environment for exploring bodily experiences. The body was generally described as a separate object and body parts were attributed with independent autonomy and agency. Interesting interactions occurred when the practitioner 'interpreted' palpable clues, explaining the body to the patient. This may parallel reflective mirroring in psychotherapy, which aims to integrate fragmented aspects of the psyche. It is possible that integrating mindfulness with touch-based therapy may offer possibilities for developing more embodied understanding about chronic pain and its impact.

Discussion: Despite a theoretical and philosophical commitment to patient-centred, holistic care, this data shows that it is difficult to do. Interventions were primarily based on objective, realist philosophical assumptions about the nature of the body and pain. There were moments where a more integrated, embodied approach showed promise in bridging the gap between a separated mind and body. Discourse Analysis may be a promising research method for exploring process in healthcare interventions which claim to offer a bio-psychosocial approach.

We still need Virchow

Ahlzen, Rolf

Rolf.Ahlzen@liv.se

The fundamental changes in the scientific basis of clinical medicine that are often dated back to Virchow's cellular pathology in the 1850'ies paved the way for massive breakthroughs in the treatment of a number of mankind's most devastating maladies. The ever closer cooperation between the sciences and the clinical researchers, and the socialization of clinicians into the epistemology of the natural world – these became the corner stones of medical progress.

For over 150 years this basic “model” has in many important respects served us well. The assumption that disease is a localized dysfunction in tissues that causes distressing symptoms or threatens life has in no way lost its relevance and potential to provide new therapies for wide-spread disorders like dementia, cardiovascular disease or cancer. When critique is levelled against “the biomedical model”, it is often simplified and does not acknowledge that this model looks different when it is a tool for medical research, from when it follows clinicians into their encounters with suffering persons. Most physicians do enter into an intersubjective exchange with those who want their help and do show interest in the lived reality of their patients. They do sense that causality is often far more complex than they have learnt. They lack a theory and often also training for handling such situations.

Hence, I want to argue that “the biomedical model” needs to be refined and to be more complex so that it is capable of incorporating multifactorial and other types of complex causality. It is, however, very much alive and should so be. All clinical practice should depart from and return to the epistemology of the first person, of the lived world. The epistemology of the body, as described by the sciences, is best seen as a necessary and invaluable abstraction from the lived reality of the suffering patient. This requires a redressing of the balance of the two perspectives in medical education, clinical research and clinical practice.

Biomedical enhancement: a remedy without a diagnosis

Ahola-Launonen, Johanna

johanna.ahola-launonen@helsinki.fi

In this paper, I elaborate the paradigmatic literature of biomedical enhancements by conducting conceptual analysis of enhancement and medicine, and argue that the paradigm of enhancement is based on an unreal neutrality. The key concept in the literature of biomedical enhancements is *making better people* by the use of such technologies. It is suggested that many characteristics such as intelligence, optimism, self-discipline, a sense of humor, or general well-being, could be increased by the use of genetic engineering or chemical neuroenhancement.

The paradigm of enhancement situates itself in the discipline of medicine, but it remains a question whether it shares any relevant epistemological and normative framework with medicine. Medicine has a long history, and even if it is not a unified discipline, its object appears clear: cure individuals by making them reestablish their ‘normal’ state. The object of medicine is the pathological and normal, defined through a diagnostic pathway.

In contrast, the enhancement paradigm leaves its objects undiagnosed as if there was a common agreement on their definitions. The disciplinary transfer between these two paradigms is examined by showing that enhancement only borrows from medicine the remedy-oriented language evacuating the diagnostic one. The notions used are never clearly and explicitly defined, but they can only be evaluated through a norm, especially when the

aim is to intervene and manipulate these characteristics. In order to define and understand the concepts, the causes of these phenomena must be understood and diagnosed. Reductionist diagnosis is criticized in medicine and there is no reason why enhancement should escape this accusation.

Medicalization and women – positional shifts between women and the medical profession

Anderssen, Jorid

jorid.anderssen@uit.no

Medicalization is often understood as a process where a growing number of human problems are defined and treated as medical problems. Medicalization has been a topic in sociological literature since the early 1960s. Women health activists problematized the medicalization of women's lives, and their passive role in relation to medical experts. The goal was equally for women and men. Women activists and others worked to make women problems visible, educate women about their own body, and women's right to choose in health matters.

Today there are many actors in the field of health and illness. The doctor's dominance has been challenged. New technology and new actors provide new knowledge about illnesses. The risk conceptions and lifestyle changes alter the way we adjust to and understand health and illness. In the new public health the individual is responsible for her health choices. This opens up for individualized interpretations of health and illness, and a more consumer-oriented health care has underpinned the individual right to choose. Such changes have affected women's relation to health and illness, and how they position themselves in relation to health care.

The modern health consumption has been questioned, including modern women's use of health services. Women's growing use of for instant C-section and cosmetic surgery has been questioned by both doctors and others. The present paper discusses the women's position in relation to today's medicine and women's position in the medicalization debate. Is medicalization a suitable description of women's consumption of health today? How is the modern woman empowered, and how does it challenge the relationship between women and the medical system? Through examples from my own research I will discuss contemporary understanding of women and medicalization.

Can advance directives be used to consent to research participation in the event of dementia?

Andorno, Roberto; Gennet Eloïse; Jongsma, Karin; Elger, Bernice

roberto.andorno@uzh.ch

Over the past decade, significant efforts have been made in Europe to facilitate the use of advance directives for medical treatments in the event of future decisional incapacity. In contrast, the possibility of using advance directives to consent to research participation in the event of dementia remains largely unexplored. Both ethical guidelines and legal regulations in Europe are virtually silent on this matter.

Advance research directives (ARDs) have a moral advantage over the current system, which relies on the exclusive consent of the legally authorised representative of the incapacitated person: *participants themselves*, while still competent, are able to express their preferences about their participation in future or ongoing clinical trials should they lose decision-making capacity. In this way, ARDs could help to solve the problem posed by the lack of information

about the willingness of dementia patients to be enrolled in clinical trials, and facilitate the task of proxies in making decisions, while ensuring a greater respect for the personal preferences and values of participants. Without such directives, family members are placed in the difficult role of having to make decisions based on the presumed wishes of the patient or on the assessment of his or her best interests, which are not obvious when no direct benefit is expected. In addition, ARDs can potentially contribute to increase the number of clinical trials involving dementia patients and facilitate the development of specific drugs for this population.

This presentation aims, first, to address the specific ethical and legal challenges that pose the use of advance directives for dementia research, and second, to consider whether there is a place for these documents in the current European legal framework. In particular, issues regarding informed consent, the role of the proxy, and the level of acceptable risks and burdens will be analysed.

Causation in scientific methods and the medically unexplained

Anjum, Rani Lill; Eriksen, Thor Eirik; Mumford, Stephen

rani.anjum@nmbu.no

Scientific methods are supposed to guarantee the quality of our research. But they do more than this. They define what counts as evidence, what counts as a cause, and what counts as a result. Any science that looks for causes must therefore do so with a pre-understanding of what causation is. This understanding is often tacit and unexamined, yet it forms the basis of our scientific practice. In medicine, for instance, population studies such as randomised controlled trials (RCTs) are thought to offer the strongest evidence of causation. But this method is based on a difference-making notion of causation and also on a frequentist interpretation of probability. These are not neutral or unchallenged philosophical theories.

Does it matter scientifically how we understand causation philosophically? To a great extent, we argue. About 30 percent of all symptoms reported to doctors in Europe and other industrialised countries today are so-called medically unexplained (MUS). These include conditions such as chronic fatigue syndrome (CFS/ME), irritable bowel syndrome (IBS), low back pain (LBP) and fibromyalgia (FM). MUS researchers have not been able to find a common set of causes, a definite psyche-soma division, or even clear-cut classifications for these conditions. Each patient seems to have a complex and unique combination of symptoms and a unique expression of the condition.

These conditions are often depicted as outliers: atypical illnesses where standard causal explanation fails. They are then approached as epistemic problems, where a solution can be found by doing more of the same. In contrast, we take the problem of MUS to be a symptom of a deeper philosophical problem: how to detect causation in cases of complexity and heterogeneity.

Hume thought we could only understand causation as a relation of regularity between discrete, essentially unconnected types of event. From this, an orthodoxy has developed which has affected the way causation is understood within the medical model: 1) robust correlations, 2) difference-making, 3) probability raising, 4) same cause, same effect. This paradigm is tacitly accepted in many scientific methodologies, especially in the health sciences. Evidence based medicine is premised on the idea that what is true of a given population should be directly applicable in individual clinical decisions. What works for most people should also work for the patient. Such external validity only holds if we assume that individual propensities can be derived directly from statistical frequencies.

An alternative to this orthodoxy is a recently developed theory of causation, called causal dispositionalism. This theory emphasises complexity, context-sensitivity, tendency, singularism and holism. While these features are problematic for the orthodox understanding of causation, they are central to MUS and other complex diseases. By changing our philosophical framework for understanding causation, we must also change our scientific practice. This includes upgrading the status of clinical experience and mechanistic knowledge. Methodologically, this means that experimental methods and N of 1 studies should be favoured over statistical methods.

Customising the Asian face: Does cosmetic surgery lead to medicalisation of racial features?

Aquino, Yves Saint James

yves-saint-james.aquino@students.mq.edu.au

In East Asian countries, the ever-growing popularity of facial cosmetic surgery has generated various debates about the implications of the practice. Ethical discussions focus on how cosmetic surgery is portraying race-identifying facial features in a negative light akin to a pathology—given that the most common cosmetic procedures are blepharoplasty (eye lid surgery) and rhinoplasty (nose job). Both procedures invariably alter a person's appearance, modifying features that are typically associated with being Asian. Since these “Asian” cosmetic procedures remain to be performed by surgeons and medical professionals, critics of the practice question the legitimacy of the subspecialty as a medical practice, suggesting that it is leading to unnecessary medicalisation of Asian features.

Medicalisation as a phenomenon arises when a traditionally non-medical problem is defined in medical terms or under a medical framework; or, alternatively, it could be instigated by introducing an intervention that lies within the purview of medicine. Analysis of studies involving debate about Asian cosmetic surgery suggests two possibly overlapping models of medicalisation, with the predominance of either model depending on where the studied population is located. The first is the treatment model, which views cosmetic surgery as a remedy for “pathologised” Asian features in Western societies where Caucasian features are considered mainstream and/or ideal. The second is the enhancement model, typically used by scholars evaluating Asians living in a predominantly Asian society; it considers the surgery as a way to improve the normal, albeit unwanted, Asian features in reference to a predominant beauty ideal.

This paper will present the findings from an empirical study that investigates the extent of either the remedial treatment model or the enhancement model of medicalisation in Asian cosmetic surgery by examining websites of surgery clinics, analysing the terms, language and images associated with the cosmetic procedures. More specifically, the study will present the content analysis of websites hosted in South Korea and Australia, as both countries are experiencing a growing number of aesthetic surgery clinics for Asians, although with varying degrees of uptake. The results will identify the relevance of the two models of medicalisation in the conceptual, ethical and social foundations of cosmetic surgery in particular, and medical practice in general.

Balancing burdens and benefits in animal research

Arnason, Gardar

gardar.arnason@uni-tuebingen.de

To be ethically justifiable, research using animals is supposed to have benefits which outweigh the harm caused. The requirement of weighing harms and benefits leads immediately to three problems: How do we evaluate the potential harm, how do we evaluate the potential benefits and how do we weigh one against the other. I will consider these three problems in the specific context of neurological research using nonhuman primates. I will argue that the evaluation of harms and benefits in any rational and objective way is highly problematic and that the results of such evaluations are incommensurable. Hence, any rational weighing or balancing of burdens and benefits, in the context of primate research in particular and animal research in general, is impossible. I then outline how it is nonetheless possible to make a moral decision about animal research based on expected harms and benefits.

Self-determination of the elderly in icelandic nursing homes

Árnason, Vilhjálmur; Stefánsdóttir Ástríður

vilhjarn@hi.is

In this paper, we will present and analyse a study (Stefánsdóttir Á. and Árnason V. 2005) that was conducted among resident of five nursing homes in Iceland. The aim of the study was to find out to what extent people living in nursing homes could decide matters of everyday life. They were asked about whether they had themselves decided to move to the nursing homes, about their privacy and personal belongings in their homes, how they could control their daily living, such as bathing times, what to wear, meals, bedtime and reception of guests. They were also asked whether they would prefer to have more control over these things than they actually had. After presenting the main results of the study, we will show how they were analysed in terms of the notion of self-determination and the legal framework about services for the elderly in Iceland. We also reflect on the effect it has on the self-determination of the residents that their homes are in effect health care institutions which medicalizes the environment. Finally, drawing on more recent study (Björnsdóttir K., Stefánsdóttir G. and Stefánsdóttir Á. 2014) on autonomy in the lives of adults with intellectual disabilities, we will reflect on how self-determination of the elderly in Icelandic nursing homes could be improved. In both cases, the opportunities for people to make choices in their everyday life is dependent upon their relationship with their carers and the quality of support they receive.

From medicalization to biosociality: Lessons from genetics

Arribas-Ayllon, Michael

Arribas-Ayllonm@cf.ac.uk

Medicalization has ceased to be a useful concept for critical analysis. It implies the excessive reach of medical authority that presses everything into a mould, a single essence of normalization subjecting all manner of pathologies and behaviours to social control. It was the product of a culture of suspicion that thought in terms of vast spaces of enclosure and overarching processes that objectify and conceal the otherwise social conditions of health and disease. These critiques have served their purpose having partly contributed to the deprofessionalization of medicine; though the “golden age” of clinical medicine was already

in decline – eroded by new political rationalities on the horizon. The new analysis of power that appeared in the 1970s began to grasp this crisis of institutions. “Medicine” was no longer conceived as a single model but a vast “assemblage” of practices and relations in which the clinical judgment of the physician was reconfigured in terms of the market, the corporation and the sturdy consumer. Some have identified the increasing capitalization and technologization as twin developments that define the politics of medicine in the 21st century. New concepts are needed, more refined and less bludgeoning, to evaluate this new field of heterogeneous developments of which medicine plays a part.

The “new genetics” offers a useful case study for evaluating contemporary biomedicine. In the early 1990s it was thought that advances in genetic technologies would herald a new age of determinism and reductionism. The concept of “geneticization” embraced the same kind of totalising logic as its medical cousin, raising concerns that redefining health and disease as “genetic” would objectify individuals and constrain their freedom. However, geneticization failed to explain the productivity of genetic knowledge, the heterogeneity of identity politics, the indeterminacy of genetic causality and the new “pastoral” relations forming within the genetics clinic. Rather than biology becoming a metaphor of society from which there was no escape, it would lead to new conceptions of life and new relations to expertise understood as circulatory networks of cultural practice. The new analysis attests to the ways in which contemporary biomedicine aligns conduct with neoliberal values of autonomy, responsibility and choice. Far from inducing resignation and passivity, it conceives a terrain of biological politics in which new forms of sociality begin to appear. Terms such as “biosociality” invite us to think that we have always been artificial. The task is not of policing the division between the natural and the cultural but of dissolving the category of “the social”.

This paper explores how biomedicine today operates within a multidimensional space, where new forces operating “beyond the state” are reframing what it means to be a living being in a living world. In this contested field of biological politics, “medicalization” is no longer good to think with because it cannot analyse the new organisation of powers that govern life processes.

Medicalization and pathologization: Can the tension between prevention, prediction and health be avoided?

Aurenque, Diana

diana.aurenque@gmail.com

The talk explores the relationship between medicalization and pathologization in the context of preventive medicine (lifestyle and health promotion) and in consideration of new genetic predictive technologies (genetic tests to predict monogenic and multifactorial predispositions to different diseases) as well. The aim of the talk is to show that there is a fundamental tension between the concept of prevention and health, and that this tension increases as a result of the use of predictive genetic tests. I will argue that the tension is grounded in different concepts and understanding of health. In order to develop this claim, I will expose 1) the difference between two different concepts of health: a) “health” as an ideal state and positive concept (prevention) and “health” as a factual state and negative concept (lack of disease). Following this differentiation, 2) I shall analyze the tension that occurs between the health concept of preventive medicine and the subjective perception of one’s own health (from a phenomenological perspective). Here I argue that this tension can manifest itself in a harmful manner, namely, as a medicalization, i.e., as an excessive concern for health that ultimately leads to an accelerated pathologization. As a next step, 3) I will show that the trend of pathologizing in preventive medicine is exacerbated by the use of predictive genetic tools.

For this purpose, I will explore by way of a philosophical reflection the general influence of technology in our life world in order to better understand the effects of pathologizing predictive medicine. In conclusion, 4) I will argue that the tendency to medicalize, and narrowly speaking, to pathologize health is based on the heterogeneity of the concept: health has different meanings in different contexts. Therefore, it is evident that the actual phenomenological experience of the body, and not merely the results offered by genetic predictive tools, should still be considered to be the best reason for employing medical means.

The bio-medical model and therapeutic drug discovery

Badcott, David

badcott@tiscali.co.uk

The presentation will concentrate on the perspective of the research-based pharmaceutical industry and make a case for the “indispensability” of the bio-medical model. The industry continuously seeks to discover, develop and market new, safer and more effective medicinal drugs. But where to begin? There are four main starting points (1) From lay or ethnobotanical sources (e.g. such as a plant reputed to control or alleviate a particular disease or illness, (2) From random screening of animal or botanical materials in tropical forests or under the sea (e.g. microorganisms, crustaceans etc.), (3) by chemical manipulation of “known” therapeutic molecular structures, (4) by “designing” a potential drug that will interact with an identified target site or system in the body associated with the disease.

For the purposes of drug discovery, as stated by Massoud et al. (*Principles and philosophy of modelling in biomedical research*, 1998) “Models are an indispensable ingredient of the scientific method; as deductively manipulatable constructs, they are essential to the evolution of theory from observation”. Drug discovery presumes in each of the processes outlined above the validity of the bio-medical model and that there is/are (a preferably) discrete active site(s) within the human or animal body wholly or mainly responsible for a disease and which can be selectively targeted for activation or blockade. The main difficulties which must be addressed by other means are (1) the vexed question of human individuality, informed by an increasing understanding, and the challenges and opportunities of pharmaco-therapeutic profiling, pharmacogenetics/pharmacogenomics and (2) fundamental philosophical and pragmatic concerns regarding the much-debated relationship between disease and illness.

The paper will strenuously defend the continuing use of the bio-medical model in therapeutic drug research and explore the means by which this can be seen as largely beneficial, and compatible with opposing critical or indeed supportive views, touching on the work of Christopher Boorse and others.

Brain rhythms as potential targets for intervention in cognitive dysfunctions – An ethical approach from a humanistic perspective (Human Dignity)

Barilan, Michael

ymbairlan@gmail.com

Two key elements of the ethos of human dignity is an open-ended conceptualization of the human being; and freedom of every person from subjection to the arbitrary or unauthorized will of any other person. The first part of the talk will present the historical background, philosophical argument and practical implications of these ideas.

In light of this theoretical background I will examine the notion of direct intervention in neural mechanisms, with special emphasis given to the metaphysical and phenomenological dimensions of manipulation of mind/self (themes related to the notion of the "embodied mind" ; "brainhood" and the like).

I will argue that as long as the intervention is specific, aiming at a measurable targets, and free from pretensions of "enhancing", "improving" or "fixing" the person, brain rhythms interventions may be acceptable, even valuable. The moral assessment of which depends mainly on the ultimate target of intervention.

In the third part I will offer an outline of such assessment, inspired by the philosophy and psychology of wisdom, especially work by Sternberg, Baltes and Staudinger and by Davidson work on weakness of will.

According to Sternberg, wisdom is the meta-skill of balancing self-care with cares for others. Baltes and Staundinger have elaborated a more comprehensive theory of wisdom as a meta skill. In their model, wisdom requires the capacity to prioritize values and chosen goals and revise them in response to changing circumstances. Excessive attachment to any one goal might be unwise. It follows that motivation enhancement might be unwise as well. Similarly, in order to qualify as "enhancement" (rather than manipulation), overcoming weakness of will (as well as emotional and cognitive alterations) require a wisely organized set of values as to justify high ranking of the preferred value to the one currently desired most.

Contemporary social change and medicalization

Barnet, Robert

phbobmd@gmail.com

The theme of this conference is *medicalization* a term popularized by Ivan Illich most especially in *Medical Nemesis* (1975).

In 1988 Illich wrote: "We find that bio-ethics is not an independent discipline speaking to biotechnology, but an enterprise created specifically for biotechnology." Is that where we are today? Have we become part of an enterprise? Almost thirty years later major changes have taken place worldwide.

1. There has been the assertion and recognition of greater individual autonomy
2. Families are smaller
3. Social mobility has increased
4. There is greater life expectancy with an aging population
5. Many, especially the elderly, endure longer periods of frailty and dependency requiring special assistance and care.
6. There is a diminished sense of community.
7. There is growing cultural diversity
8. Electronic communication is increasingly "the norm."

Illich's interest in medicalization was rooted in his concern, not about health care per se, but about the various dependencies and exploitation created in contemporary society. Illich looked at what was happening in education, the Church, and society in general. When he focused on health care technology and medicine he discovered examples of exploitation, often masked by the public's trust in "good physicians" who had dedicated their lives to serving humanity.

Illich's concern has not solved the problem of medicine's tendency to create inappropriate dependencies and to exploit a public increasingly vulnerable. Rather, it now more important than ever to critically examine current examples of medicalization.

I will explore how contemporary societal changes predispose some to medicine's overarching reach, highlight the critical importance of the physician's altruism and commitment to the patient, and use the growth of for-profit hospice in the U.S. to illustrate a current example of medicalization with the ability to victimize both families with dying members and society. I will explore the concept of population health and health care's new interest in the social determinants of health as movements that Illich would have embraced as antidotes to medicalization and its ills.

In the last 30 years we have seen renewed calls for physicians to embrace the altruism central to medicine as a moral profession and essential to maintaining the public's trust. At the same time the seduction of what I call the Five P's, power, position, prestige, profit and politics, continues to pervert medicine's original calling. Strikingly absent from the Five P's as human drivers is the primacy of people, patients, the public. We need to seek new ways to deepen the moral formation of physicians to ensure their trustworthiness and immunity to exploitative tendencies.

Ethics plays a role in the medicalisation of death

Benton, Kathleen

kathleendeloach1@hotmail.com

There is a vicious cycle that begins slowly at the onset of a chronic illness and extends to the end of life. This cycle is at the heart of what makes modern medicine both brilliant and burdensome. The patient may be diagnosed with chronic renal disease, for example. And after resources are exhausted with a primary care physician or medical home, needs to seek specialist care and eventually, long-term dialysis. The patient may be diagnosed with Chronic Obstructive Pulmonary Disease (COPD) and likewise, may need to seek specialty care, and eventually long-term O2 or even bi-pap support. With an aging population, more will live longer, the majority will live older and many will live chronically ill. In both patient cases above, the need for specialists and aggressive measures may move to chronic infections, issues with nutrition and eventually, chronic hospitalizations. Each time the patient is discharged stable and well enough to leave, the only absolute will be the expectation for readmission, until the progression becomes the end stage and the end stage becomes death. The cycle may be lengthy, and may steal all quality of life from the patient.

The ethics consult may come in-house, when "futility" is dictated on the chart and family is "unreasonable" about care. Should the ethics involvement instead be in the medical home, assessing what resources have been used and what the patient and family deems best early in a disease? This paper will examine the principle of justice, one used far less in modern medicine than that of autonomy and often viewed as a paradox. This paper will argue that the principles should work together and ethics should break down the walls of the hospital consult and move outward into the medical home before the progressive chronicity of disease presents. Resources like specialists, dialysis and respiratory equipment should absolutely be provided as they are available, especially in considering the more vulnerable indigent populations. But further resources like palliative care, advanced care planning, understanding the progression of disease and a timeline of care needs, should be the first resource provided to all, despite the ability to pay. Communication in healthcare, both inpatient and outpatient is a silo, thus no gatekeeper helps to focus the patient/family on dignity and living, only the next step is considered repeatedly until all perspective on dignity is lost. Ethical concerns, pre-emptively would allow the patient and family a clear look at goal setting, boundary forming and the ability to autonomously participate in resource allocation and thus, the principle of justice is achieved through choice.

The perfectionist fallacy in transhumanist thought

Bessemans, Chris

chris.bessemans@ucll.be

Nick Bostrom, one of the most prominent scholarly thinkers about and defenders of post- or transhumanism, writes in the introduction of his widely discussed paper '*In defense of post-human dignity*' that bioconservatives's central concern is that human enhancement technologies might be 'dehumanizing'. The worry, which has been variously expressed, is that these technologies might undermine our human dignity or *inadvertently erode something that is deeply valuable about being human but that is difficult to put into words* or to factor into a cost-benefit analysis.¹

My purpose in this paper is precisely to put into words why the practical transhumanist attitude 'inadvertently erodes something that is deeply valuable about being human'.

While I tend to agree with Michael Sandel's² analysis that what is troubling about enhancement and genetic engineering is a drive to mastery, which may destroy our appreciation of the gifted character of human powers and achievements, Sandel's arguments seem to fall short in several respects. Firstly, he seems to fail to explain (at least to the transhumanist) *why* the gifted human practice is (intuitively) appreciated or considered to be of utmost value. Secondly, and more importantly, Sandel does not seem to provide a clear answer to the question why enhancement would be dehumanizing. Instead, Sandel seems to argue for these points in a derivative way and explains why embracing enhancement and genetic engineering would alter key features of our moral landscape: humility, responsibility and solidarity. In doing so, Sandel misses out on the possible strength of his initial argument and the discussion runs to risk to be transferred to the issue whether enhancement and engineering would alter these key features.

By making references to the debate on meaningfulness and by relying on the anti-utopian work of Aurel Kolnai³, I will deepen Sandel's initial, fruitful insight and, firstly, explain why we appreciate our given human practice (and why we cannot do otherwise) and, secondly, why enhancement would be dehumanizing. Consequently, I will be able to show that the transhumanists their theoretical and practical attitude to embrace enhancement technologies is a threat to our meaningful existence as human beings.

In brief, my conclusion is that the serious entertaining of transhumanist ideals as a significant and compulsory reference point for practical thinking is a manifestation of a mentality which is in a deep sense contradictory, delusional anti-realist, and dehumanizing. The problem with transhumanism is that it entails a kind of contradiction: the attainment of the ideal non-alienating state of being necessitates a revolutionary, total alienation and disruption.

¹ Bostrom, Nick, 'In defense of post-human dignity', *Bioethics*, 3 (2005) 19, p. 203 (my italics).

² Sandel, Michael, 'The case against perfection. What's wrong with designer children, bionic athletes, and genetic engineering', *The Atlantic Monthly*, 3 (2004) 293, p. 51-62.

³ Kolnai, Aurel, *The Utopian Mind and Other Papers. A Critical Study in Moral and Political Philosophy*. Dunlop, Francis (ed.), London, Athlone, 1995, 217 p.

An ethical approach to the taking care of the elderly at the end of their lives: for a social learning of the dying process as a collective project

Boitte, Pierre

pierre.boitte@univ-catholille.fr

From the observation of the deep modifications occurred in the relation to death in our medicalized societies over the last few decades, including the advent of palliative medicine, this presentation could be organized in two stages.

The first part consists in developing the contemporary end-of-life context. Considering the end of life as a complex process including biological, psychic, relational and even organisational factors seems to be crucial in order to provide a more accurate view of the complexity pertaining to end-of-life care relations. Three types of stakes for an end-of-life dedicated medicine then appear, consisting in: acknowledging the complexity of decision-making processes; setting up multi and inter-professional teams to serve the patient's quality of life and the quality of the relationship; adapting care-providing institutions to the current evolutions, particularly within the scope of palliative care. Two specific stakes for an ethical reflection about the end of life are then highlighted: taking actors' questions into account and developing individuals' and institutions' learning capacities.

The second part deploys three perspectives aiming at providing oneself with the means to assume this questioning about the taking-care process devoted to the elderly at the end of their lives and contributing in that way to the respect of the dignity of these persons at the end of their lives.

The point is first to underline the importance of a reinvention of ethics as centred on the construction of the subject, on the basis of human and social sciences, then to appeal to the *care*-thinking in order to deal with care in our capitalistic societies as well as with the institutions providing this care, and finally to put forward a reflexive, contextual and pragmatist conception of ethics, endowed with the capacity to help us face practically the numerous questions and difficulties related to end-of-life situations.

The conclusion is a plea for a social learning of the dying process as a collective project. It must be possible to elaborate other end-of-life forms of life, to imagine other management and taking-care devices, to design other decision-making processes so that the matter should be to learn, individually, institutionally and socially, how to die better.

What type of discourse is present concerning ethical issues in Croatia?

Borovecki, Ana

abor@mef.hr

In everyday life we are often using we are using written or spoken communications that we call discourse. For Michel Foucault discourse describes “an entity of sequences, of signs, in that they are enouncements (énoncés)”. An enouncement is an abstract construct that allows the signs to assign and communicate specific, repeatable relations to, between, and among objects, subjects, and statements. Discourse is composed of semiotic sequences (relations among signs) between and among objects, subjects, and statements. The term discursive formation conceptually describes the regular communications (written and spoken) that produce such discourses. Recently in Croatia there was a significant amount of discourse present in relation to different ethical issues: physician-physician relationship, physician patient relationship, conscious objectors in medical practice. In this contribution we will apply this approach in analysis of discourse present in Croatia when it comes to these and other ethical issues. We aim through this analysis to elucidate discourse present in Croatia as

a “systems of thoughts composed of ideas, attitudes, courses of action, beliefs and practices that systematically construct the subjects and the worlds of which they speak.”

Gamete Provision and Legal Parenthood

Brandt, Reuven

r.brandt@lancaster.ac.uk

Many countries have adopted regulations specifically governing the ascription of legal parenthood when assisted reproductive technologies are used to create children. A common practice is to absolve ‘third-party’⁴ gamete providers of legal parental responsibilities when their gametes are used by patients in an officially licensed clinic. This marks a departure from a more traditional legal view that often treated genetic parentage as sufficient grounds for imposing parental obligations, like mandatory child support. On the surface, this more nuanced approach to determining legal parenthood might seem correct – after all many people think that it would be unjust to burden gamete providers with parental obligations. Though I agree that gamete providers should not be considered legal parents, that legal parenthood is in-part determined by whether conception takes place within a highly medicalized context is morally problematic.

I argue that the medical credentials of the individuals assisting in creating pregnancies are morally irrelevant for determining which individuals ought to be considered the legal parents of the resulting children. Furthermore, I argue that in many cases pregnancies by use of third-party gametes are possible without resorting to the risky and technically involved procedures, like IVF, whose performance we might think should be limited to licensed medical professionals. Taken together, these arguments suggest that the status quo, which requires individuals to seek medical assistance when wishing to procreate using third-party gametes, is not defensible on strict ethical grounds. Rather, the policy seems in place to act as a pragmatic criterion for distinguishing ‘true’ gamete provision cases from other cases where the state wants to hold genetic parents legally responsible (e.g. one-night-stand cases). Consequently, part of the motivation behind medicalizing gamete provision is to serve pragmatic regulatory purposes that are independent from legitimate medical concerns.

I further argue that the current framework cannot be defended on the grounds that it poses only a minor inconvenience that serves an important regulatory function. Using fertility clinics can be both costly and time consuming. Furthermore, it subjects individuals to scrutiny about their reproductive choices, and often requires that individuals allow strangers access to intimate aspects of their lives. This kind of intrusion into personal reproductive decisions would not be acceptable in the case of unassisted reproduction, and so it is unclear why it is permissible when third-party gametes are used for reproductive purposes. Additionally, since same-sex couples require third-party gametes if they wish to reproduce, the status quo amounts to an additional and unnecessary barrier to procreation for members of this community who already face many obstacles to becoming parents. Lastly, I argue that non-medical alternatives could easily be put in place to fulfil the pragmatic legal role that the current practice serves.

⁴ By third party I mean gamete providers who do not intend to parent, but provides gametes to individuals who do.

Self-medicalisation: A trend for the future?

Bruckamp, Kirsten

bruckamp@gmail.com

Medicalisation is a common and variegated term. Viable alternatives for its definition may refer to the relevance of medical expertise, the application of medical interventions, or the exertion of social control, e.g. by pathologisation. Over several decades, classic medical activities for diagnostics and treatments have been complemented by efforts in prevention, health promotion, palliative care, and enhancement. Consequently, case studies in these areas may also unearth new variants of medicalisation. Self-medicalisation, a novel term that has not been examined widely to date, may be defined as a process by which an individual makes fundamental aspects of herself or himself subject to medical interpretation or intervention.

One apparently obvious candidate for self-medicalisation is self-medication. In fact, the former term has first been used in conjunction with the latter in the academic literature (cf. S. Fainzang in *Cult Med Psychiatry* 37(3): 488 – 504, 2013). Nevertheless, the expression self-medication implies that the self is understood as an acting entity that exercises autonomous control over medication. Self-medicalisation, in contrast, also means that core constituents and activities of an individual are regarded as the passive objects of medical attention and examination. Therefore, self-medication, while it may be a phenomenon of medicalisation, only captures one aspect of self-medicalisation.

Contemporary approaches to body monitoring and body tracking may be regarded as prime examples for self-medicalisation. They include methods to acquire data about internal states (e.g. wakefulness, cardiovascular functions) and performance measures (e.g. in sports). Body monitoring can also extend to nutrition, and thereby, it touches on the fundamental capability of living organisms to take in food. The relevance of body tracking for the self is mirrored in alternative names for it, such as life-logging and self-surveillance. The relationship to medicine in the sense of medicalisation stems from the medical and technological knowledge that is necessary to gain and interpret the data.

Self-medicalisation appears to be on the rise, given the examples of body monitoring that have emerged in the last few years. Motivations may include health promotion, disease prevention, enhancement, curiosity, and entertainment by using technical opportunities. Several reasons make a future rise of body tracking likely, e.g. technical advancements, availability of medical information to laypeople via modern media, and a general increase in client-initiated health-related measures.

Ethical concerns relate to the areas of data protection and confidentiality. Also, health care systems could eventually be strained, if citizens frequently sought medical attention for negligible reasons. In case of abnormal results, the users can seek medical attention fairly immediately. Thereby, they rely on medical experts much earlier than others who ignore faint or temporary bodily phenomena that may or may not be signs of diseases. Moreover, closer examinations of the users' subjective motives would be informative to better assess its personal and social relevance. Although body monitoring may sometimes be driven by purely autonomous interests, the possibility of a heightened sense of insecurity and concern should be evaluated and addressed separately from any bodily findings. The sociological analysis of self-medicalisation is only just beginning.

Extended fertility preservation - just a medical reality or women's right?

Caenazzo, Luciana; Tozzo, Pamela

luciana.caenazzo@unipd.it

Fertility preservation is an emerging field that provides the opportunity to maintain reproductive health to all those patients who either have to receive medical treatments or want to preserve their gametes to postpone childbearing for other reasons (age-related fertility preservation). The majority of patients who can benefit from fertility preservation techniques are cancer patients.

In recent decades, a social trend toward delaying childbearing has been observed in women of reproductive age. In fact a novel technico-medical innovation was commercialized for non-medical reasons to healthy, ostensibly fertile women, who wished to postpone motherhood for various reasons such as educational or career demands, or because they had not yet found a partner. As a consequence, these women may be affected by age-related infertility when they decide to conceive, and fertility preservation techniques may also be considered indicated in this population.

However, although the American Society of Reproductive Medicine recently removed the experimental label of oocyte vitrification, information about the long-term follow up of children is still unavailable, and more data are needed about the efficiency of oocyte vitrification at more advanced ages.

While the option for cancer patients to freeze oocytes in the face of treatments that may render them infertile is generally considered in a positive light, offering the same option to healthy women is met with new ethical challenges.

Oocyte freezing consists of two separate steps that are clearly distinct in time: at the time of the first step, women who request social freezing are healthy persons who ask for a procedure that results in stored oocytes that may or may not be used, depending on the further course of their lives. Nevertheless, an ethical discussion on this topic should address some questions that will be described.

From a medical point of view we have to consider the balance between the risks of the procedures (ovarian hyperstimulation, oocyte pick up and pregnancy) and the benefits, for the mother and the child. In bioethical terms the balance between the respect of the woman autonomy (including the reproductive autonomy) and the beneficence both for the mother and the child. Should the Assisted Reproductive Technology (ART) funding be extended also for "social egg freezing" in the perspective of resources allocation for Public Healthcare System?

Finally, in a gender perspective, we should consider that social sperm freezing is less debated and more accepted, so, a possible argument in favour of social freezing could be to avoid discrimination between men and women. In this case, we wonder if equality between men and women should be achieved by erasing biological differences between them, or if social freezing is the embodiment of the trend in society to accept less and less the finiteness and unavailability of the human life. In the same vein, must equality in the job market go hand in hand with further medicalisation of reproduction? Social freezing is advertised to achieve extended fertility preservations. But we wonder if it is the proper solution to the problem or if it could also create further problems.

Unfit for the *present*: Defending the medicalisation of personality

Campbell, Michael

michaeldavid.campbell@utoronto.ca

Literature on the ethics of Moral Bioenhancement has focused largely on altering humans to prevent behaviours that may contribute to the destruction of our species. Aside from the cataclysm foreseen by thinkers like Savulescu and Persson, a great deal of damage is done *to* people *by* people where the effects are experienced locally and immediately. These harmful actions, such as sexual assault, psychological bullying and domestic violence, can have profoundly negative psychological and physical effects on individuals, which when considered in aggregate, bring great costs for health care systems. If the ability to intentionally act in ways that cause psychological and/or physical harm to others were significantly restricted or eliminated altogether, substantial public health benefits would follow. This particular type of moral enhancement involves human intervention to alter personality with particular ends in mind. This practice is controversial because one's personality is deeply entangled with – and perhaps even co-extensive with -- the locus of subjective ontological value, which is oft regarded as morally off limits to human meddling. Despite this controversy, I argue that we ought to pursue opportunities to alter human personalities to prevent people from intentionally causing harm to others, and that this endeavour should be a high priority for publically funded research.

Questions remain as to which behaviours should be prevented, which should be permitted and/or enhanced, and by what means (e.g., some combination of biological and social intervention). Where can we find answers to such questions? A starting point might be the medicalised notions of personality found in psychiatric nosology – for example, the Diagnostic and Statistical Manual of Mental Disorders – 5 (DSM 5). In the DSM 5, some constellations of personality traits (i.e., personality disorders) are pathologies when the people who possess them have a rigid tendency to behave in ways that cause subjective distress and/or harm to others.

Yet this notion of disorder as pathology is challenged by the Constructivist epistemology that underlies the Recovery philosophy of mental health care. This version of Constructivism is based upon an Idealist metaphysic that “criticizes the notion of ontological reality (i.e., reality as it is in itself)” and depends on individual perception.⁵ Constructivism also deeply embeds Hegel's Dialectic. According to Slade, “A key theme in constructivism is the role of disorder, as a trigger for dialectical development ... Disorder is necessary for the development of complex systems, so processes of disorder are not pathologized as opponents of health.”⁶

I argue that the medicalisation of personality survives the challenges posed by Constructivism. While the DSM 5 paradigm conceives disorder as pathology, this paradigm is not incompatible with the Idealist-Constructivist framework. Rather, the goodness and rightness of medicalising personality are subsumed by the framework by adding Hegel's doctrine that universals are not pure and can contain other concepts (i.e., that an antithesis can be deduced from a thesis because it is contained in the thesis). I conclude that the further medicalisation of personality is morally good insofar as it catalyses the end of human induced suffering.

⁵ Slade M. Personal recovery and mental illness: A guide for mental health professionals. New York: Cambridge University Press, 2008 (P. 54).

⁶ Slade M. The epistemological basis of personal recovery. In: Recovery of people with mental illness: Philosophical and related perspectives. Ed: Abraham Rudnick. Oxford: Oxford University Press, 2012.

The medicalization of men's reproduction

Campo-Engelstein, Lisa; DeCoster, Barry

campoel@mail.amc.edu

Although men's bodies serve as the dominant norm in most of medicine, women's bodies are more likely to be medicalized and there is much more discussion in the bioethics literature about the medicalization of women's bodies. Medicalization's paradigmatic example is birth, but other common examples include menstruation, menopause, pregnancy/infertility, and bodily aesthetics. Men's medicalization is often either ignored, labeled as a sort of abnormality, or raised in a poorly framed argument to show that medicalization impacts both women and men (and thus ought not be a concern). When addressed, most discussions of the medicalization of men's bodies have been limited to deviance (e.g. alcoholism, homosexuality, and hyperactivity) with the goal of returning to normality and health. Recently, there is a growing movement to recognize the ways in which other areas of men's lives can be medicalized, especially their sexuality (e.g. erectile dysfunction and low testosterone syndrome).

The medicalization of men's reproduction remains under-theorized, which is in stark contrast to the significant medicalization of women's reproduction. Our goal in this paper is to begin to fill this void by examining the medicalization of men's reproduction and comparing it to the medicalization of women's reproduction. Specifically, we argue that whereas the medicalization of women's reproduction can function to both reinforce and resist dominant power structures, the medicalization of men's reproduction mainly maintains or enhances privilege and adherence to hegemonic masculinity.

For evidence, we analyze examples from both ends of the reproductive spectrum: infertility and contraception. While both men and women can be diagnosed as infertile, this medicalized diagnosis impacts the identities of men and women in dramatically different ways. Women tend to find infertility more devastating than men and experience it as "spoiling" their identity, especially their identity as woman, wife, and mother. Men report remaining unchanged in their personal identities; infertility is a problem to be solved with medical intervention, but not an identity-altering experience. Here, we note the important difference in how medicalized technologies empower and disempower men and women differently.

In the case of contraception, we claim that whereas female contraceptives are generally seen as enhancing women's autonomy, male contraceptives (condoms and vasectomy) are sometimes viewed negatively because they do or are thought to alter men's genitals and sexual functioning, which are the pillars of masculinity. The resistance many men have to using male contraceptives as well as societies' lack of interest in developing new male contraceptives are at least in part because male contraceptives violate dominant norms of masculinity (e.g. men as virile).

By taking a gendered lens, we are able to recognize the ways in which and the factors that contribute to why men's and women's health, especially reproduction, are medicalized differently. We call attention to men's reproductive health as a topic warranting further bioethical analysis in order to promote better (non-oppressive) healthcare policies and practices.

Irrational choices – the challenge to the normative ideal of informed consent

Chanska, Weronika

weronika.chanska@gmail.com

Individual autonomy is a foundational principle in Western bioethics, and there is universal agreement that patients should make autonomous decisions regarding their medical care. In the field of health care patients' autonomy is protected by the theory and practice of informed consent. In a specific decisionmaking context, informed consent is deemed to be reached if the person is competent, if adequate standards of disclosure and understanding about the intervention are met, and, finally, if consent to the proposed intervention is given voluntarily. It is commonly believed that most patients when have understood a scientific explanation, will use it to make rational or logical choices regarding their medical treatment.

At the same time other branches of academic inquiry (such as psychology of choice and behavioral economy) that scientifically and experimentally explore the ways in which people make choices inform us that peoples' behavior is rarely driven solely by rational thinking. Just the opposite, the empirical evidence shows that people are emotional beings swayed by the winds of irrationality even as they attempt to make the most logical and rational of choices.

These findings pose the challenge to the standard of informed consent deep-seated in the contemporary medical practice. I will apply the findings to demonstrate that the idea of informed consent is indeed based on the normative notion of a rational human subject and aims at promoting choices that such a perfect subject would make. In that sense the doctrine of informed consent is better suited to "educate" people (instructing them how they should act) than to imitate the way they make choices in real life. I will argue that the oblivion of the normative nature of informed consent has created unresolved tension between ethical requirements concerning the doctor-patient relationship and the habits and needs of many patients.

This tension is particularly striking within the context of making advance decisions. Psychological research demonstrates that across a wide variety of decision contexts people show limited ability to predict their affective and behavioral reactions to future situations. Which in turn makes highly unlikely their capability of making rational decisions regarding future events and health states .

I will conclude with some remarks on whether it is possible to design the process of making decisions regarding future medical interventions that on the one hand takes into account the peculiarities of individual patients and pursues their needs, and on the other comes close to the normative ideal embedded in the standard of informed consent.

Medico-legal challenges regarding termination of pregnancy for severe congenital anomalies: Implications for international human rights laws and women's reproductive autonomy

Chima, Sylvester C

chima@ukzn.ac.za

Termination of pregnancy (TOP) or feticide for severe fetal anomalies is ethically and morally challenging and maybe considered illegal in countries with restrictive abortion laws. While diagnostic modalities such as fetal ultrasound, magnetic resonance imaging (MRI) and genetic screening have improved prenatal diagnosis internationally, these technologies remain scarce in many African countries thereby making prognostication and counselling regarding abortion difficult. Ethical dilemmas such as women's autonomy rights often

conflict with a fetus' right of personhood. In many jurisdictions, pre-viable fetuses are not considered persons with legal rights. However, in countries with restrictive abortion laws the fetus may be imbued with the right of personhood at conception, thereby making abortion illegal, exposing doctors and patients to potential criminal prosecution. The birth of a severely disabled baby with independent legal rights creates further conflicts between parents and clinicians complicating healthcare decision-making.

Nevertheless, TOP for severe fetal anomalies is supported by international human rights laws such as the International Covenant on Civil and Political Rights (ICCPR). This was demonstrated in the case of *KL v Peru*, where a pregnant woman with an anencephalic fetus, was denied TOP due to restrictive abortion laws. The UN Human Rights Committee (HRC) concluded that this amounted to cruel and inhuman punishment violating articles 2, 7, 17, and 24 of the ICCPR which oblige State parties to provide just administrative action, liberalize abortion laws and compensate victims. The HRC findings are supportive of the protocol to the African charter on rights of women where Article 14 (2) (c) obligates African countries to "protect the reproductive rights of women by authorizing medical abortion in cases of sexual assault, rape, incest, and where continued pregnancy endangers the mental and physical health or life of the mother and the fetus."

Irrespective of maternal decision to accept or refuse TOP, the psychological and emotional impact of a malformed fetus, often lead to moral distress and post-traumatic stress reactions in mothers/parents. Clinicians must be sensitive to the ongoing dynamic in order to safeguard the rights of mother and child. Doctors have ethical and legal obligations to provide timely and accurate antenatal diagnosis with full disclosure to enable informed choice. Failure to do so may lead to negligence and liability for 'wrongful birth' or 'wrongful life' when children are born with severe physical or neurodevelopmental disorders, as demonstrated in the South African cases of *Stewart v Botha* 2008 and *Friedman v Glicksman* 1996. In *Botha*, the Supreme Court of Appeal held that healthcare practitioners who failed to diagnose and inform parents of a fetal anomaly so that they could have considered TOP, were liable to pay damages for "wrongful birth", while the *Glicksman* Court held that failure to inform a woman that she was at greater risk of having a child with congenital anomaly, meant her doctors were negligent. Misdiagnosis and poor management also impact on appropriate use of scarce healthcare resources in resource poor settings. This paper analyses ethical challenges in managing two African neonates delivered following attempted feticide/TOP for prenatally diagnosed CNS anomalies.

Medicalization and demedicalization of sexuality: The strange case of hypersexuality and ephebophilia from DSM-IV-TR to DSM-5

Codato, Francesco

francesco.codato@unive.it

Pathologies related to sexuality have always played a role of big importance in the DSM-drafting, only just thinking that the reformulation of the current diagnostic system is due in large part to the reflection resulted by the cancellation of homosexuality which was expected as a pathology in the DSM (1973). The recent DSM-5, which comes from a work lasted 12 years, has brought to the fore the extraordinary case of two sexual pathologies: hypersexuality and ephebophilia. Since their birth in early 2000s these two diseases have represented the symbol of the new DSM disorders and both of them have suffered the same destiny: from being an icon of the developments in the diagnostic field, during the years they have become the subject of biting criticism about the strictness of the classification provided by the DSM until the final decisions of their exclusion from the last version of the DSM-5

published in 2013. The two diseases represent the very essence of the concept of medicalization: for 5 years they have been diagnosed and treated, then these diseases have been suddenly disappeared and a person who could be defined sick of “hypersexuality” was suddenly considered healthy. Even though they have been excluded from the DSM-5 marketing campaigns, the great presence in the media and in many scientific articles has ensured that they are still present in the collective imagination and, for this reason, the people still associate some specific behaviours with these (ex-) psychiatric diseases. The report that I would like to propose aims to summarize the genesis and the development of these diseases through the reconstruction of the debate which has involved the epistemological introduction and the following elimination of these two disorders from the DSM-5, in order to show not only the history of these two ex-pathologies, but also the American Psychiatric Association (APA) internal mechanism used to create a new disease and a new form of medicalization of life. The final purpose of my presentation is to put a philosophical and epistemological criticism to the diagnostic system of sexual diseases proposed in the DSM-5 by comparing it with the one provided by the DSM-IV-TR. This analysis will allow me to show the character more normative than therapeutic of the DSM-5 in sexual field and the importance of the classification of mental disorders related to sexuality for the entire DSM diagnostic system.

The contradiction of the DSM-V diagnostics criteria. A problematic distinction between mental and organic disease.

Corazza, Vera

vera.corazza@student.unisi.it

The DSM-V supports the psychiatric-drugs therapies with the idea that mental illness is biological. Moreover, the manual is divided in a detailed catalogation of each single mental disease, corresponding to the ICD-10 codes. However, the diagnosis proposed by DSM-V is mostly based on the observation of the behaviour because there are no biological markers, apart for a small group of diseases called "organic diseases". In this different denomination and in the distinction between neurologic-mental-systemic disease we can underline the contradiction inside the manual: mental diseases are curate with drugs, as organic disease, but defined and managed differently. Moreover, the diagnosis made after observation, inevitably subjective, leads to the impossibility of maintaining the precision that the catalogation pretends to have.

The dualistic premiss is a consequence of the explicative gap in the biologic explications of most mental diseases. We can consider the example of "schizophrenia spectrum": the criteria that define schizophrenia are paradoxically more similar (methodologically speaking) to the diagnostic criteria of, for example, the recently discovered "caffeine-intoxication disorder", because they are both diagnosed by observation. At the same time, schizophrenia is clearly distinguished, in the differential diagnosis, from the "body dysmorphic disorder" because of the clearly organic origin of this one. However, it often results that schizophrenia symptoms are exactly corresponding to the dysmorphic disorder (here the necessary ad hoc differential diagnosis), but that schizophrenia is not directly connected to a biologic cause (Frith, 1995).

A second problem comes by the subjective diagnosis, (Frances, 2014): in this way every conduct can theoretically be interpreted in the light of the vast list of diseases proposed by DSM-V. The idea that each disease has a biologic cause, even if this is not defined, allows the use of psychiatric drugs in most of the mental disease. This leads to the demolition of the border between health and illness, and the devaluation of the idea of mental illness, as it is seen as something that affects almost everyone, in the more of 400 diseases presented in the DSM-V.

What should be done to resolve these problems is to reassess all the diagnostic criterias starting from the single deficits (Frith, 1995; Grandin, 2013) again with the example of "schizophrenia spectrum" that includes symptoms that are very different from each other and probably would present different markers. A new catalogation, instead of the one maintained by the DSM-V still based on old unscientific theories, could be helpful to determine the way research should be conducted to find biologic markers, focusing on pragmatic evidence and neuroimaging techniques (Grandin, 2013) instead of old theories and responses to psychiatric drugs, as the DSM-V suggests. The DSM-V should underline the risk that leads the absence of diagnostic markers, especially as the criteria used to distinguish between organic and mental disease is the absence of explicit biologic causes in the mental disease. In this way it could be possible both to fight the stigmatization that the mental illness leads to, and to prevent the medicalization of society.

Defining infertility and the medicalisation of the wish to become a parent

Cutas, Daniela

daniela.cutas@umu.se

The aim of fertility treatments is to treat or counter the effects of infertility. At first sight, one might be tempted to define infertility as the inability to reproduce. When determining access to such treatments, a distinction is often drawn between medical (clinical) reasons for the inability to reproduce, versus social reasons: with the implication that medical reasons are more, or the only, worthy of medical treatment or financial support. However, the definitions of infertility currently in use when determining access to fertility treatments are not simply about clinical inability to reproduce, but presuppose a number of social criteria. For example, according to the World Health Organisation, infertility is “a disease of the reproductive system defined by failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse” (Zegers-Hochschild et al 2009: 1522). Such a definition will include situations in which there is nothing wrong with the clinical ability of any particular individual to reproduce (that we know of) and will exclude, for example a woman without ovaries or an azoospermic man who did not have “12 months or more of regular unprotected sexual intercourse”. The definition presupposes sexual intercourse, presumably between individuals of different sex, of reproductive age, etc. – and indeed, in some legislatures, all these conditions are made explicit, and accompanied by supplementary requirements, such as that the couple be married or cohabiting. What is proposed as a conceptual definition is in fact very much a normative one.

In this talk, I will analyse current definitions of infertility and I will show that the distinction currently drawn between medical and social reasons for claims to access infertility treatment is misleading. Together, the definitions and the distinction serve to discriminate between individuals who fit certain expectations of close personal relationships and desirable prospective parenting, and those who do not, in a way that is unfair and unjustified. By claiming that the current definitions such as the one cited above are “clinical” (as specified at the source), policy makers medicalise the wish to become a parent of individuals who fulfil a number or non-clinical requirements, and leave out those who do not but are otherwise (sometimes clinically) unable to reproduce; they reward certain types of relationships and chastise others. Finally, I will argue for making all and any rationale for granting or denying access to infertility treatments explicit. Reproduction and parenting are deeply important goals for many individuals. Therefore, the explicitness and justifiability of reasons for privileges, oversight or denial of access to parenting are important for reasons of social justice.

Reference:

F. Zegers-Hochschild, G.D. Adamson, J. de Mouzon, O. Ishihara, R. Mansour, K. Nygren, E. Sullivan, S. Vanderpoel for ICMART and WHO (2009) 'International Committee for Monitoring Assisted Reproductive Technology (ICMART) and the World Health Organisation (WHO) revised glossary of ART terminology, *Fertility and Sterility*, 92, 5, 1520-24.

Evil Euthanasia – Why the ethical analyses of Nazi Euthanasia are still not good enough

Dahl, Ellen Støkken; Nortvedt, Per

ellensdahl@gmail.com

Many articles are written on the Nazi Euthanasia program and on doctors' participation in the Holocaust from the perspectives of Social Psychology, History and Social Sciences. Bioethics and Moral Philosophy, on the other hand, has had less to say.

The works on the Nazi Doctors that are indeed written in Bioethics are mainly centered around research ethics, the horrible experiments on human subjects, and on whether or not the data extracted from these experiments should be used. The slippery slope analogy is also discussed in full. Our project, however, focuses more on the actual people that committed the atrocities, and on their motivations and justifications for killing.

Bioethics has originally focused on principles and arguments for right moral conduct. We agree with Jonathan Glover who calls for a reorientation of ethics in his seminal work on human evil in the twentieth century (Buchanan 2010, Glover 1999). He argues that perhaps primarily, ethics should discuss standards for human behavior, and the challenging and complex phenomena of good and evil.

So where does the evil in men come from? Theories are presented. Some claim that human empathy is vulnerable to numbing (Lifton 2000), and that standard moral principles have little actual motivational impact on human behavior. We keep hurting each other, even if we know that it is wrong. Morality seems to break down relatively easy when confronted with peer pressure, extremist ideologies (Vetlesen 2005), professional hierarchy and authority (Welzer 2013).

How does this knowledge on evil impact medical professional ethics, and the moral collapse that happened among German doctors that participated in the Nazi Euthanasia program?

How could the Nazi Doctors kill thousands of patients without remorse?

We argue that the analyses in Bioethics on the Nazi Doctors perspective in the Euthanasia Program are too shallow. We need a new angle. We need a new, more thorough ethical analysis of Nazi Euthanasia in a Bioethical perspective.

References:

Buchanan, Allen. 2010. "Social Moral Epistemology and the Tasks of Ethics." In *Ethics and Humanity*, edited by N. Ann Davis. Oxford: Oxford University Press.

Glover, J. 1999. *Humanity: A Moral History of the Twentieth Century* (Jonathan Cape). London.

Lifton, Robert Jay. 2000. *The Nazi Doctors; Medical Killing and the Psychology of Genocide*. 2000-ed ed: Basic Books.

Vetlesen, Arne Johan. 2005. *Evil and human agency: Understanding collective evil-doing*: Cambridge University Press.

Welzer, Harald. 2013. *Gjerningsmenn*. Oslo: Forlaget Press.

Orphan drugs: Victims of personalized medicine?

De Clercq, Eva; Elger, Bernice S.

eva.declercq@unibas.ch

«When you hear of hoof beats, think horses, not zebras». This proverb is often used in medical schools to teach students that physicians first have to consider a common diagnosis when they examine a patient's symptoms rather than searching for an exotic medical explanation. The aphorism typifies the traditional diagnostic protocol, but leaves out the number of "zebras" which populate the world. In fact, despite the rarity of a single rare disease, it is not unusual to have a rare disease. Therefore, rare diseases constitute an important challenge to both medical care and public health services.

Orphan drugs are medicinal products that are developed for the diagnosis, prevention or treatment of rare diseases. Access to orphan drugs can vary between individual EU member countries. Problems of accessibility are mainly due to the exorbitant prices that pharmaceutical companies charge for these medicines in order to compensate for the high R&D costs. Historically, they have been fully covered by public or private health insurers, but recently the budget spent on these drugs has come under close scrutiny. This has raised an intense debate on whether they should be granted special status.

Supporters of the special status thesis increasingly invoke citizens' apparent willingness to put greater resources towards the funding of orphan products. There is an upward trend to identify this social concern with the rule of rescue and to dismiss it as irrational in some obvious sense. Our aim is to show that this identification is based upon an inconsistent use of the notion of identifiability in much of the scholarly literature on rare diseases. The same misinterpretation lies at the heart of the increasing association between orphan drugs and the movement toward personalized medicine (PM). It is argued that the growing link between these two industries has led to the recent focus on the problem of resource allocation for orphan drugs. The fear is that with the further expansion of personalized medicine more and more people will claim the identified victim status to receive expensive therapies that benefit only small populations and that this will place the healthcare system under a tremendous financial pressure.

On the basis of the analysis of identifiability, we will show that rare diseases and classical rule of rescue situations as not fully equalized cases and that the link between rare diseases and PM is unwarranted. We advance the argument that societal preference towards rare diseases is far from being a matter of special consideration, but is an integral part of people's moral framework. Hence to dismiss it out of hand might, in the long run, undermine the solidaristic foundations of public healthcare.

The risks of medicalizing risk

De Grandis, Giovanni; Halgunset, Vidar

giovanni.de.grandis@ntnu.no

The idea of medicalization was introduced in the early 1970s to identify and criticize a trend: the "process whereby more and more of everyday life has come under medical dominion, influence and supervision" (Zola 1983, p. 295; see for instance Freidson 1970, Zola 1972, Illich 1976). However in more recent years more positive aspects of medicalization have been acknowledged (e.g. Broom & Woodward 1996, Chodoff 2002, Parens 2013). Acknowledging the elements of truth in both views, in this paper we use the concept of medicalization as an evaluatively neutral one in an attempt to map the reasons why it can be seen as both positive and negative.

Besides mapping the negative consequences of medicalization highlighted by its critics (e.g. the political costs in terms of either loss of liberty [Skrabanek 1994; Fitzpatrick 2000] or public retreat from healthcare and social medicine [Clarke & Shim 2011]; or the costs in terms of the diminished ability of individuals for self-care and coping [Illich 1976]; or simply the economic costs [Conrad, Mackie & Merhotra 2010]), we point out 4 positive features of it: 1) it often promotes action to bring symptomatic and psychological relief to patients; 2) it relieves some of the burden for informal carers; 3) it empowers public health initiatives; 4) it is a marker of the progress of the biomedical sciences.

A vision that may seem to have the virtues of medicalization while avoiding some of its pitfalls is that of a medicine proactive rather than reactive, where the emphasis shifts from treating illness to promoting wellness. A predictive, personalized, preventive and participatory approach to medicine—as exemplified by Hood & Friend's (2011) P4 medicine—promises to cut financial healthcare costs and reduce the number of misdirected medical interventions by making therapies more targeted to each patient's characteristics. P4 medicine is also presented as empowering both physicians and patients. Identifying risk factors at an early stage will enable timely action by health practitioners, or even enable patients to adjust their lifestyles so as to avoid diseases altogether. So can P4 medicine reduce the unwanted consequences of medicalization?

Within our proposed framework that constructs medicalization as a phenomenon with both desirable and unwelcome features, we focus on the potential of P4 medicine (in particular of its predictive and preventive ambitions) to drive an unlimited expansion of the domain of what has been called “pre-sickness” (Maturo 2012), a phenomenon that can feed all the undesirable sides of medicalization. We argue first that the expansion of pre-sickness is related to how the notion of health risk is constructed. Second we show that predictive-preventive medicine brings with it a number of specific medical, ethical, legal, psychological, economic and cognitive mechanisms or trends towards risk inflation in such a way that it lowers the threshold of pre-sickness. Our analysis unravels some of the epistemic and ontological questions raised by the notions of risk and pre-sickness: two concepts that are closely entangled with the idea of uncertainty and with the bounds of our knowledge.

References:

- Broom, D H & Woodward, R V (1996), “Medicalisation Reconsidered: Toward a Collaborative Approach to Care”, *Sociology of Health and Illness* 18 (3), pp. 357-378.
- Chodoff, P. (2002), “The Medicalization of the Human Condition”, *Psychiatric Services* 53 (5), pp. 627-8.
- Clarke, A. & Shim, J. (2011), “Medicalization and Biomedicalization Revisited: Technoscience and Transformations of Health, Illness and Biomedicine”, in Pescosolido et al (eds.), *Handbook of the Sociology of Health, Illness and Healing*, Springer, New York, pp. 173-200.
- Conrad, P., Mackie, T. & Merhotra, A. (2010), “Estimating the Costs of Medicalization”, *Social Science & Medicine* 70, pp. 1943-7.
- Fitzpatrick, M. (2000), *The Tyranny of Health*, Routledge, London and New York.
- Freidson, E. (1970), *Profession of Medicine. A Study of the Sociology of Applied Knowledge*, University of Chicago Press, Chicago and London.
- L Hood & S H Friend. 2011. “Predictive, personalized, preventive, participatory (P4) cancer medicine”, *Nature Reviews Clinical Oncology* 8, 184-187
- Illich, I. (1975), *Medical Nemesis. The Expropriation of Health*, Calder & Boyars, London.
- Maturo, A. (2012), “Medicalization: Current Concept and Future Directions in a Bionic Society”, *Mens Sana Monographs* 10 (1), pp. 122-33.
- Parens, E. (2013), “On Good and Bad Forms of Medicalization”, *Bioethics* 27 (1), pp. 28-35.

Skrabanek, P. (1994), *The Death of Humane Medicine and the Rise of Coercive Healthism*, The Social Affairs Unit, London.

Zola, I.K. 1972, "Medicine as an Institution of Social Control", *Sociological Review* 20, pp. 487-504.

—1983, *Socio-Medical Inquiries*, Temple University Press, Philadelphia

Why we should not speak of medicalisation

Dehue, Trudy

g.c.g.dehue@rug.nl

Since the 1990s, the number of people with a psychiatric diagnosis has rapidly increased - particularly in affluent countries. Consequently, even governmental bodies now speak of 'medicalisation', doing so in a derogatory sense. I argue that this word not only describes an unwanted process but also suggests that medics and their patients are its main and only culprits. In this way, the word medicalisation draws attention away from the political developments that are essential to the increase of people with a psychiatric diagnosis. The phenomenon is part of present-day health politics that on its turn is part of economic politics. Stated differently, those who keep their hand on the open tap are reproaching the mopping team of the aquatic nuisance.

Medicalizing (&) enjoyment. On La Mettrie's the art of enjoyment and related matters

De Kesel, Marc

marcaugustdekesel@gmail.com

The origin of modern 'medicalization of health' is to be found in the Age of Enlightenment, more precisely in the scientific materialism that has been launched then. One of the important pamphlets within the birth of materialism as paradigm for medical sciences is *Man-Machine* (*L'homme machine*, 1748), by the physician/philosopher Julien Offray de La Mettrie. The text however does not contain concrete directives for health care. Concrete directives, however, even about health, are all over the place in the other writings of La Mettrie, for instance in his *The art of Enjoyment* (*L'art de jouir*, 1951), which often is described as an apology for sexual pleasure. Sexual and other enjoyment guarantee good health.

In my paper I examine the way in which eighteenth century medical materialistic theory consider enjoyment. How, in the theoretical writings of that time, enjoyment is treated as a materialistic phenomenon? Why enjoyment is a rather marginal topics there, while in other, non-scientific writings of the same authors (Diderot among others), enjoyment is discussed frequently.

The thesis I defend is that, behind that dichotomy in materialism's treatment of enjoyment, there is the problem of the modern subject. The paradigm of the subject, which is repressed by the materialistic paradigm, still haunts that theory in the way it tries to come to terms with the phenomenon of enjoyment. Today's attempts to 'medicalize the subject' have their roots in that still unresolved dialectics between 'repression' and 'haunting'.

Is digitalization the end of medicalization as the subject knows it?

De Vos, Jan

JanR.DeVos@UGent.be

A central tenet of medicalization (especially as it directly concerns subjective matters and ties in with [neuro]psychologization), has always been that it requires a knowing subject. That is, medicalization entails, besides the administration of the drug also the administration of a good dose of theoretical knowledge. The diagnosis of clinical depression, for example, passes over an education of the patient: what you suffer from... and as we know from brain research...

However, now with the digital turn –sweeping not only through our lives but also through the (para)medical sciences– have we not finally left behind theories and knowledge? It's no longer the scientist or (neuro)psychologist who knows (and wants us to know), it's the computer and Big Data discerning patterns and from there implementing therapeutic strategies that are closely monitored so as to adjust the treatment almost in real time. While before the medics and the (neuro)psy's wanted us to become their pupil, the computer doesn't care if we know or not: we're simply nudged and steered in the "smart environments" surrounding us: we are not expected to know what driving us, we're driven by Big Data.

Is this the end of medicalization as the subject knew it, the end of the reflective and confessional modes of auto-discipline? Is it time then to devise a critique of the digital codes and algorithms that ground digitalization? Or are things yet more complicated?

Why do we love what we used to hate? Medicalization at a turning point

Devisch, Ignaas

Ignaas.Devisch@ugent.be

Since Ivan Illich launched his critique on the medical establishment, medicalization became synonym for a perverted evolution in western health care. Since then, it is almost exclusively used as a critique to the oppression by the health establishment of which the subjects suffer, culminating in the call for resistance against this system.

But as the world has changed profoundly, including medicine, since Illich criticized medicine, and so must our analysis of it be. Today, instead of resisting against medicine or medicalization, most of us do everything they can to participate in it. Unless our governments prevent us from it, are we not doing everything we can to overuse the system, to consume medicine as much as possible?

In my presentation, I analyze this evolution from the work of sociologist Jean Baudrillard and his concept of 'implosion' (the negative of explosion) to make clear that medicalization is at a turning point. Or, we plead for neutrality, go 'beyond' it and loose every analytical potential of this concept; either we unravel its current analytical potential and attempt for a renewed analysis in contemporary society and medicine. If social critique will still be of importance in tomorrow's medicine, much will depend upon the way we deal with this crucial question.

The medicalization of human reproduction: The case of prenatal screening

De Wert, Guido

g.dewert@maastrichtuniversity.nl

The term 'medicalisation' is regularly used in moral debates on preventive medicine. This holds true for debates on reproductive screening, particularly prenatal screening, as well.

Medicalisation, however, is an equivocal term; it has both a descriptive and an evaluative meaning. It has been (rightly) proposed that it may be better to disentangle the term and make the 'hidden' objections explicit in moral debates. In the ethics of prenatal screening for fetal abnormalities, like Down syndrome, these hidden objections mostly regard possible threats to respect for reproductive autonomy, proportionality (of possible benefits and harms) and justice, articulated from different, partly converging, perspectives, like the 'fetalist', the 'feminist' and the 'disability rights'-perspective. It will be argued that these objections are not really convincing – even though they raise some important points to consider. As the future development of 'fetal personalised medicine' (FPM) will, no doubt, increasingly generate (experimental) treatments for fetal abnormalities, a timely ethical reflection on this scenario is urgently needed. Obviously, it can be anticipated that FPM will also be framed as a form of medicalization. It will be shown that the term medicalization is, again, not very helpful to address the ethical issues involved – and particularly, that the 'disability rights' critique regarding FPM is flawed.

Should we revise medicalization theory in the light of personalized medicine and the medicalization of risk?

Di Marco, Silvia

sdmarco@fc.ul.pt

“Medicalization” is a sociological concept that refers to the process whereby nonmedical problems (deviant behaviors and life events) become understood and treated as medical problems (Conrad, 2007; Davis, 2010). Such process can occur at different levels: conceptual (medical vocabulary or models are used to define a problem); institutional (organizations develop a medical approach to tackle a problem); interactional (doctors and patients meet face-to-face, medical diagnose and treatments are indicated) (Conrad and Schneider, 1980; Conrad, 1992; Halfmann, 2011). Currently, the driving forces of medicalization have shifted from medical establishment and social movements to pharmaceutical and biotechnological industry, individuals (as consumers), and managed care (Conrad, 2007). Simultaneously we have witnessed the emergence of the medicalization of risk (physiological risk factors and genetic susceptibility) (Klawiter, 2002; Lupton, 1993).

The aim of this presentation is to analyze Personalized Medicine (PM) in the light of medicalization theory, and to revise medicalization theory in the light of the problems posed by PM. There are many definitions of PM, but for the purposes of my study I use that provided by Simmons and colleagues (2012). For these authors, PM will deliver its promises of tailored medical intervention only if it is understood as “a coordinated, strategic approach to patient care that broadly applies the concepts of systems biology and personalized, predictive, preventive and participatory care (known as P4 medicine)” (2012:86).

From the analysis of this model it emerges that PM reinforces the role played by industry and patients in the medicalization process, and expands the medicalization of risk. I further examine the latter point distinguishing between therapy-driven and diagnosis-driven medicalization of risk, and stressing that what is medicalized in these cases are neither deviant behaviors nor life events, but rather physiological or genetic “states,” as it were. These are clearly “non-events” from the perspective of the lived experience of an individual or a community, and can only be conceptualized as medical problems in terms of risk, surveillance and prevention. Thus, by focusing on the notion of risk, PM reinforces both the epistemic and ontological status of the “potentially ill.”

To deepen our understanding of the idea of risk-related medical problems, and of the related figure of the potentially ill, I turn to philosophy of medicine. I draw on Schwartz’s analysis of

the concept of risk-related disease (Schwartz, 2008), and on Giroux's discussion of the problems posed by the notion of risk factor to the demarcation between normal and pathological (Giroux, 2010), to highlight the normative status of the notion of risk (conceptual and institutional levels of medicalization), and the consequences that this normativity entails in terms of doctorpatient relationship (interactional level of medicalization). In the light of these considerations I suggest that for medicalization theory to be fruitfully applied to PM, it has to encompass not only deviant behaviors and life events, but also non-events turned into medical problems by the medicalization of risk (figure of the potentially ill). This in turn emphasizes the need to renovate the debate over medical surveillance and over medical creation of new subjectivities.

References:

- Conrad P. (1992), Medicalization and social control, *Annual Review of Sociology*, 18:209–232
- Conrad, P. (2007), *The Medicalization of Society. On the Transformation of Human Conditions into Treatable Disorders*, Johns Hopkins University Press, Baltimore
- Conrad P. and Schneider J.W. (1980), Looking at levels of medicalization: A comment on Strong's critique of medical imperialism, *Social Science & Medicine*, 14(1):75–79
- Davis, J.E. (2010), Medicalization, social control, and the release of suffering, in *The New Blackwell Companion to Medical Sociology*, ed. W. Cockerham, Wiley-Blackwell, Singapore, pp. 211–241
- Giroux, E. (2010), Les facteurs de risque et le problème de la démarcation entre le normal et le pathologique : une analyse épistémologique, *La Revue de médecine interne*, 31:651–654
- Halfmann, D. (2011), Recognizing medicalization and demedicalization: Discourses, practices, and identities, *Health*, 1–22
- Klawiter, M. (2002), Risk, prevention and the breast cancer continuum: The NCI, the FDA, health activism and the pharmaceutical industry, *History and Technology: An International Journal*, 18(4):309–353
- Lupton, D. (1993), Risk as moral danger: the social and political functions of risk discourse in public health, *International Journal of Health Services*, 23:425–35.
- Schwartz, P.H. (2008), Risk and disease, *Perspectives in Biology and Medicine*, 51(3):320–34
- Simmons, A. et al. (2012), Personalized medicine is more than genomic medicine: confusion over terminology impedes progress towards personalized healthcare, *Personalized Medicine*, 9(1):85–91

Ethical signposts for clinical geneticists in secondary variant and incidental finding disclosure discussions

Dierickx K; Christenhusz GM; Van Esch H; Devriendt K
Kris.Dierickx@med.kuleuven.be

While ethical and empirical interest in so-called secondary variants and incidental findings in clinical genetics contexts is growing, critical reflection on the ethical foundations of the various recommendations proposed is thus far largely lacking. We examine and critique the ethical justifications of the three most prominent disclosure positions: briefly, the clinical geneticist decides, a joint decision, and the patient decides. Subsequently, instead of immediately developing a new disclosure option, we explore relevant foundational ethical values and norms, drawing on the normative and empirical ethical literature. Four ethical

signposts are thereby developed to help guide disclosure discussions. These are: respectful sharing of the clinician's expertise; transparent communication; epistemic modesty; and respect for the embedded nature of the patient. We conclude by considering the most common current disclosure positions in the light of the four ethical signposts.

Adverse outcomes of in-vitro conceived very low birth weight twins and patient autonomy in assisted reproduction

Dollberg, Shaul; Reichman Brian; Lerner-Geva, Liat; Boyko, Valentina; Levitzki, Orna; Barilan Michael Y

shauldol@gmail.com

Background: Multiple births associated with assisted reproduction technologies, especially in-vitro fertilization (IVF) with more than one embryo, have become rife. The decision on the number of embryos to transfer is controversial as many twins are born prematurely with long term or even lifelong severe health consequences, and conversely the transfer of more than one embryo may improve the chance of a "successful pregnancy". However, a key conceptual question is the construction of "success" in this context – is it measured by live-births only, as the common statistics is applied, by maternal satisfaction rate or by some long term overall health indices. As a step towards answering this question we have conducted a study on the rate of prematurity related morbidity among IVF induced multiple-pregnancies.

Methods: In order to provide updated data on the medical outcome of IVF twins, this population-based study evaluated the mortality and major morbidities of IVF conceived, very low birth weight (VLBW) twins. The Israel National VLBW infant database comprises data on >99% of all VLBW infants born in Israel. The study population composed 2,098 IVF conceived VLBW twins born from 2001-2010, who accounted for 13.5% of the 15,555 VLBW infants and only 0.14% of all live born infants in Israel.

Results: There were considerable major neonatal morbidities and mortality in the study population. A total of 316 infants died (15%) representing 5% of all infant deaths in Israel over the decade. 31.3% of infants had a severe adverse outcome of death or any major morbidity. The cumulative length of hospital stay for the 2,098 infants was 105,205 days and these infants occupied 5-6% out of a total of the 526-583 beds available nationally during this time period.

Conclusions: IVF conceived VLBW twins had a significant impact on mortality and neonatal morbidities as well as on utilization of health care resources. A policy of single embryo transfer would practically eliminate these deaths and morbidities, however it is less clear which structure of decision-making would support the best respect for maternal autonomy, the welfare of both mother and child, and considerations of justice. This study is an example of a potentially markedly negative outcome resulting from the introduction of an advanced medical technology, which may have significant ethical and legal implications. Continuous evaluation of new technologies is required to ensure that their application complies with the ethical and moral principles and responsibilities of modern medical care.

Risky play, children's welfare, and minimal risk standard

Dranseika, Vilius

vilius.dranseika@fsf.vu.lt

Children are active risk-seekers, and many of their playground and outdoors activities include risky play. A number of psychologists have claimed that opportunities for risky play are

necessary for normal psychological development, including development of capabilities for adequate assessment of risks, regulation of fear and anger, and building of confidence. Ariella Binik in her recent paper 'On the minimal risk threshold in research with children' (2014) defends a standard of minimal risk based on risks of daily life of children who "fare well". Among other things, she refers to unstructured play, including outdoors, as a necessary element of children's welfare. In this paper I argue that levels of risks that are considered acceptable and even beneficial in risky play would, however, result in unjustifiably permissive minimal risk standard.

Ethical aspects of non-therapeutic male circumcision

Earp, Brian D; Ulman, Yesim Isil; Cosgun, Erdal; User, Inci; Ozveri, Hakan

yesimul@yahoo.com

This paper deals with the ethical aspects of non-therapeutic circumcision (NTC), that is, the surgical removal of the penile foreskin from male infants and boys in the absence of disease or deformity⁷.⁸ We are specifically concerned with circumcision performed before an age of consent, since voluntary, adult circumcision raises a different set of ethical issues.

Circumcision has a long history in ancient societies of Africa and the Middle East. While it has conventionally been argued to have arisen as an early public health measure for preventing recurrent balanitis (caused by sand accumulating under the foreskin), this 'utilitarian origins' theory has been recently criticized by medical historians. A more likely explanation is that circumcision arose for ritualistic reasons, and then became rationalized later on as a form of partial prophylaxis⁹. Consistent with this view, there is a long history of circumcision's having been "medicalised" in various societies, including in the United States, at least in part to provide secular support for an often controversial religious custom¹⁰. Often described as a "simple" operation, circumcision nevertheless carries significant risks, although the likelihood and magnitude of such risk has not yet been thoroughly established¹¹. Debates about circumcision have flared in recent years, due to a number of factors: a court decision in Germany stating that circumcision constitutes a form of bodily assault, a revision to the American Academy of Pediatrics' policy on circumcision, and a recent introduction of draft guidelines on the surgery issued by the Centers for Disease Control. We analyze these developments in light of well-established ethical principles. For example, in the bioethics literature, the principle of a child's right to open future has recently been used to criticize NTC. On this view, the permanent removal of a healthy part of one's genitals before one can make an informed decision about such a procedure constitutes a violation of this right.

This paper aims to evaluate the moral permissibility of NTC, drawing on data from a quantitative study carried out with healthcare professionals in Turkey who practice the

⁷ Hutson, J. M. (2004). Circumcision: a surgeon's perspective. *Journal of medical ethics*, 30(3), 238-240.

⁸ Earp, B. D. (2015). Sex and circumcision. *The American Journal of Bioethics*, 15(2), 43-45.

⁹ Darby, R. The riddle of the sands: circumcision, history, and myth. *The New Zealand medical journal*, 2005118(1218), U1564-U1564.

Available at https://www.academia.edu/9899840/The_riddle_of_the_sands_Circumcision_history_and_myth

¹⁰ Carpenter, L. M. (2010). On remedicalisation: male circumcision in the United States and Great Britain. *Sociology of health & illness*, 32(4), 613-630; Aggleton, P. (2007). "Just a snip": a social history of male circumcision. *Reproductive health matters*, 15(29), 15-21; Hodges, F. (1997). A short history of the institutionalization of involuntary sexual mutilation in the United States. In *Sexual Mutilations* (pp. 17-40). Springer US; Gollaher, D. L. (1994). From ritual to science: The medical transformation of circumcision in America. *Journal of social history*, 5-36. Chicago

¹¹ American Academy of Pediatrics Task Force on Circumcision. (2012). Male circumcision. *Pediatrics*, 130(3), e756)

operation. In this study we will use focus group approaches, and as a continuation of the results of this study, a qualitative-quantitative study will be executed. A face to face survey method will be used as the data collection technique. We will implement the surveys in 3 full-fledged hospitals in Istanbul, Turkey. We will meet with 17 physicians in every hospital with 80% statistical power and %5 alpha rate. We are going to select these hospitals from 3 different neighborhoods according to their socio-economic status. We will extend our focus group and add different stakeholders to our future studies. The aim will be to understand how these professionals regard circumcision as being consistent (or inconsistent) with the medical-ethical values of non-maleficence, beneficence, respect to autonomy, and justice¹². Variables of interest will include the degree to which these health professionals are knowledgeable (or not knowledgeable) about the anatomy and functions of the intact penile prepuce, as well as their degree of awareness of the ethical controversy that has been building up in recent years regarding this procedure.

Medicalisation and the sick role

Edgar, Andrew

Edgar@cardiff.ac.uk

The purpose of this presentation is to explore the interrelationship between processes of medicalisation and the cultural and political construction of the modern social roles of patient and physician. Medicalisation is understood in terms, not merely, of the increasing mediation of human well-being as a medical phenomenon, but also the dominance of a natural scientific epistemology underpinning medical practice, diagnosis and research. A reading of Talcott Parsons' original formulation of the sick role (in *The Social System* of 1951) offers a snapshot of the professional culture from which medicalisation grew. The complementary relationship that exists between the sick role and the professional role of the physician serves to explicate the way in which a certain conception of the patient and physician, not least insofar as the physician's paternalistic authority over the patient is grounded in their scientific expertise, opens the way to increasing medicalisation. The conception of scientific expertise is tightly defined in terms of a linear causal model of explanation, and crucially one that marginalises patient experience. This model may be seen to lead to and reinforce the evidence based medicine as a core component of medical professionalism. A specific conception of scientific expertise, it will be argued, serves to construct both the role of the physician and that of the patient.

Non-linear causation and hermeneutic approaches to the conceptualisation and diagnosis of disease and illness allow traditional understandings of the nature of scientific expertise to be questioned, and thus the Parsonian professional and sick roles to be challenged fundamentally. This in turn leads to a de-legitimation of medicalisation. A critical reading of Parsons' account of the sick role and professional role will serve to explicate internal inconsistencies and tensions that may be resolved through appeal to alternative conceptions of scientific expertise, to non-linear causal models of causal explanation and hermeneutic diagnosis.

¹² Beauchamp, T. L. (2007). The 'four principles' approach to health care ethics. *Principles of health care ethics*, 3-10

Is biomedicalisation bad for you? The example of ageing

Ehni, Hans-Joerg

hans-joerg.ehni@uni-tuebingen.de

In an article from 2013 Eric Parens has noted that the concept of biomedicalisation is generally used by sociologists with a negative evaluative meaning. *Prima facie* it refers to a negative social trend which implies that aspects of human life are submitted to medical control and treatment, and thus medical practice extends its realm ever further beyond its legitimate reach. But is such a negative evaluation of biomedicalisation beyond an allegedly descriptive sociological approach justified from an ethical perspective? These are crucial questions for a fruitful application of the concept of biomedicalisation to bioethics. This presentation will contribute to an answer by analyzing the underlying evaluative assumptions of different concepts of biomedicalisation of ageing by Carol Estes, Adele Clarke, Sharon Kaufmann and John Vincent. In a first step, some of their main implicit or explicit evaluative assumptions – normalization of individual difference, replacing social by medical solutions, injustice, and allegedly mistaken conceptions of the good life – are analyzed and criticized from the perspective of ethical theory, in particular in regard of their justification. In a second step, some of the main concepts such as “medical gaze” are reconstructed in light of Paul Ricoeur’s concept of a “hermeneutic of suspicion”. It will be argued that the corresponding rules of interpretation, which guide such a hermeneutic discipline, also provide orientation of the implicit ethical evaluation of the examined conceptions of biomedicalisation. As an outlook, an improved application of the concept of biomedicalisation in the interdisciplinary context of bioethics will be sketched.

Prevention of what? Ethical aspects of the medicalisation of aging

Eichinger, Tobias

Eichinger@ethik.uzh.ch

Medicalisation has many faces. From the very beginning of life – planning and optimizing reproduction, childbirths in hospitals – to the end of it – dying under the doctor’s eyes or within the palliative paradigm – ranges the influence of medical thinking and acting. Medicalisation is also normative ambiguous. Whereas the defining and handling of a problem in medical terms and treatments could mean a great help and relief to the person(s) concerned, it also could lead to problematic consequences on an individual, social and conceptual level.

That complex ethical diagnosis also regards the case of the biomedicalisation of aging. On the one hand, there has been developed and introduced a lot of helpful medical innovations for elderly people delaying and alleviating the burdens of old age and keeping their activity and capacity to lead a self-determined and fulfilled life as long as possible, a development with beneficial effects which could be interpreted as appropriate answer in technoscientific and consumer societies to the ongoing rise of life expectancy.

On the other hand the increasing medical treatments and clinical age research tend to change (more or less implicit) the common understanding of what it means to grow old – and what every single person has to do in preparation of that later phase of life. Due to its process of medicalisation, aging becomes more and more a project, a project for whose course and success the individual is fully responsible. Moreover, the consequential perception of aging strongly emphasises somatic and thereby deficient bodily aspects. And finally, a quite radical but consistent step further on the path of medicalisation declares aging itself as disease that medicine has to cure, or even more to prevent before it runs its natural course.

Priority setting: Should lifestyle choices matter?

Feiring, Eli

eli.feiring@medisin.uio.no

Please recognise that you can make a significant contribution to your own, and your family's, good health and wellbeing, and take personal responsibility for it. NHS Constitution of 2012

There is an increasing recognition that non-communicable diseases (NSDs) are overtaking infectious diseases as the world's leading cause of morbidity and mortality. Health care expenditure following from NCDs may pose a challenge to the sustainability of public health care. Many of the major risk factors contributing to NSDs are potentially modifiable lifestyle factors. The aggregate consequences of individual lifestyles put strain on the public health sector. As the burden of non-communicable diseases on society increases, what used to be a private matter concerning choices of lifestyle is now seen as a public concern.

The debate on health resource allocation and rationing includes arguments in favour of the view that government should provide a criterion for denying treatment to, for according lower priority to, or for requiring a greater financial contributions from patients who are seen to be responsible for disease. People find it unfair that those who make imprudent health choices should burden those who make healthy choices, and argue that the individual must bear a share of the healthcare costs related to their health behaviour.

Others, however, find it unfair that individuals should be held responsible for health choices, regardless of social circumstances. Disease is caused by a range of different factors, among these social factors the individual cannot reasonably avoid the possibility of. Indeed, empirical studies show that disadvantaged groups of the population face greater associated health risks than other groups, and that the prevalence and the distribution of these risks contribute to health inequalities both within and between populations.

So the question remains: Is it reasonable that scarce resources are spent on treatment of diseases that, at least to some degree, could have been avoided through individual lifestyle changes? The discussion of such a question depends crucially on how lifestyle is conceived. Do individuals choose lifestyles or is lifestyles a matter of socialisation? Who is responsible for a person's way of living? What is the relationship between notions of responsibility, blame and cost-sharing? And further, how may choice-sensitive theories of distributive justice guide political decision-making within this context?

Assistive care robots for elderly with dementia: human dependency and the technologisation of elderly care

Felzmann, Heike

heike.felzmann@nuigalway.ie

Developed countries across the world are facing a shift in demographics towards increasing proportions of elderly in the population, with particularly dramatic rises in the numbers of the very elderly over 80 years old. Rates of physical frailty and dementia increase substantially in this age group, and adequately meeting their increasing care needs is becoming a significant social concern. A particular focus of care strategies internationally is to facilitate persons with dementia to continue living at home as long as possible, rather than caring for them in more restrictive (and costly) institutional settings. However, care at home requires a level of human care provision that is often not available, and the current reality is that as a consequence many people with dementia experience loneliness and neglect, resulting in accelerated cognitive and functional decline. ICT solutions have been proposed to enable persons with

dementia to continue living in their communities, including ambient assisted living technologies, companion robots, monitoring robots or assistive robots. Assistive robots in particular may provide a range of supports, including feeding, bathing, physical exercises, medication reminders, games, cognitive stimulation, and facilitation of social interaction. Overall robot functionalities are still highly specific and generally limited (especially if compared to the images of robots in the popular imagination), but they can provide practically useful services.

The recent ethical debate on the use of such robots has been wide ranging, focusing on aspects such as requirements of ethical design, privacy, safety, their impact on care and the further marginalisation of the elderly. While many contributions to the debate accept in principle that robot assisted care could be of value to the elderly, a strong dystopian undercurrent is noticeable especially in contributions dealing with the impact of robots on the nature of care for the elderly. In this paper, I will engage specifically with arguments that present robots as a technological threat to genuine human caring relationships. I will discuss these concerns from a relational ethics perspective that starts from an analysis of dependency, informed by feminist reflections on dependency and caring relationships. I will explore the interplay of dependency and independence for all stakeholders resulting from the introduction of robots to the care of persons with dementia. Given that robotic care is currently an add-on to, not a full replacement of care for the elderly, relationships between the person with dementia, their formal and informal carers and the robot are all affected. This allows a relationally more complex picture of robots' impact on care to emerge. While the use of robots needs to be considered in its wider social context, including its potentially problematic longer term implications on the delivery of care, this perspective should not replace the ethical consideration of immediate relational impacts on dependency, independence and care delivery.

The author is part of a recently funded H2020 project, MARIO, for the development of an assistive robot for elderly with dementia.

Governing the process of medicalization: The role of institutions and public society

Feys, Roel

feys@email.sc.edu

In 2013 the American Heart Association and the American College of Cardiology, two authoritative non-profit organizations, issued influential new cholesterol guidelines. The recommendations sparked immediate controversy. According to some the new guidelines overnight increased the number of people for whom statins, a class of cholesterol-lowering drugs, are recommended by as much as seventy percent. People that were previously regarded healthy or at very low risk for cardiovascular disease. Others questioned the independence of the panel drawing up the guidelines by pointing out several experts on the panel had recent or current financial ties to pharmaceutical companies. Even before the release of these latest guidelines cholesterol was deemed an illustration of medicalization, among others by Peter Conrad.

I use the example of the new cholesterol guidelines to show the process of medicalization is at least in part the result of the prevalent institutional arrangements in health care. Most health care institutions are either centralized, (quasi-)government organizations or distributed, market institutions. The American Heart Association and the American College of Cardiology being examples of the former, the pharmaceutical companies being examples of the latter. That being said, many health care institutions are hybrids and have characteristics of both arrangements.

Assuming at least some instances of medicalization (e.g. cholesterol) appear problematic, I argue the following: If institutions indeed play a role in the process of medicalization, then either existing institutional arrangements need to be changed or alternative institutions need to be designed in order to scrutinize, criticize, and frustrate suspect cases of medicalization. Commons institutions, pioneered by Nobel Laureate in Economics Elinor Ostrom, are well-suited to critically analyze the process of medicalization, either tagged on to existing institutions or as standalone organizations.¹³ Referring to the work of Jürgen Habermas, I associate these commons institutions with the concept of public society, as they can form a counterbalance against the commonplace institutions of state, large non-profit organizations in the case of cholesterol, and market.¹⁴ I suggest commons institutions cannot only act in individual instances of medicalization, but some of them might also be able to provide critical reflection on and a correction of the process of medicalization as a whole.

I support my argument by drawing upon the literature on institutional analysis, institutional change, and institutional design.

A disease model of criminal behavior

Focquaert, Farah

Farah.Focquaert@ugent.be

Human enhancement implies that humans have the ability to change their future behavior for the better provided adequate means to accomplish such changes are provided. In case of moral enhancement and the prevention of (recurring) criminal behavior, such means may involve changing the environment (e.g. addressing poverty, unemployment, incarceration) or changing the individual in question (focusing on changing the individual's behavior through behavioral and/or biological interventions). How should we as a society deal with the environmental and biological risk factors of criminal behavior? According to some philosophers and ethicists, we have strong moral reasons to avoid retribution and look for alternatives ways to rehabilitate offenders and prevent recidivism. A disease-model or public health model of criminal behavior, for example by targeting the 'criminal brain' or the 'violent brain' and/or risk factors for criminal behavior, could provide possible alternatives. A public health model aims to prevent and reduce ill health by targeting the risks factors for ill health. Similarly, a public health model of criminal behavior could target the biological risks factors (e.g., addiction, personality disorders, aggression, attention and impulse control disorders, etc.) of criminal behavior in all offenders, not just offenders that are identified as 'mentally insane'. Such a model would also focus on prevention and early screening of risk factors of criminal behavior. If focused on offenders, it would include a mental health and care approach that assesses and aims to repair the biological risk factors on a case-by-case basis.

In this talk, I will provide a hypothetical scenario in which criminal behavior is addressed by reference to a mental health and care approach (e.g. similar to dangerous infectious diseases) that focuses on dignified ways to rehabilitate offenders. I will present a scenario in which responsibility claims towards criminals are forward looking claims that involve moral answerability, demanding the restoration of past mistakes and focusing on preventing future criminal behavior, but not backward looking claims that demand retributive punishment or

¹³ Ostrom, E., *Governing the Commons. The Evolution of Institutions for Collective Action*. New York, Cambridge University Press, 1990. Print.

¹⁴ Habermas, J., *Faktizität und Geltung. Beiträge zur Diskurstheorie des Rechts und des demokratischen Rechtsstaats*. Berlin, Suhrkamp Verlag, 1992. Print

answerability in the basic desert sense. Moral answerability in this sense focuses on rehabilitation, therapy and moral enhancement to prevent recidivism.

Negotiating Death

Foreman, Thomas; Curran, Dorothyann; Kekewich, Michael

dcurran@toh.on.ca

The experience of death for many people in the western world is no longer a natural process but instead is heavily influenced by medical interventions. In his critique of the medical establishment many years ago, Ivan Illich defined the social and cultural impact of medicalization on population health and for modern medicine death is the final health challenge to intervene with. For those who are imminently dying, death is frequently interrupted by machines, drugs and fluctuating decisions regarding the application of these devices which interfere with the body's attempts to navigate a natural process.

The medical interventions applied to the last days of life have become increasingly intense while remaining ineffective; stays in intensive care, exploratory scans, surgeries, and continued intensive drug therapies have no impact on the eventual outcome of a patient's status. More recent research is exploring the reliance on medicine to cope with death, revealing an unwarranted dependency on the medical establishment and exploitation of the dying as a means to drive economic, social and cultural expectations of life and death. Illich's critiques still apply to the process of modern medicine as it relates to the experience of death; however in the navigation of the modern health care system there is much room for change in how death is 'negotiated'. What is missing is a discussion of the ways to mitigate the experience of death for the patient and family in the 21st century; how to define active dying, properly integrate palliative care and establish boundaries for use of interventions that accommodate the inextricable system of modern medicine overlaid on the natural dying process.

What does it mean to terminate a pregnancy for « medical » reasons?

Gaille, Marie

mariegaille@yahoo.fr

This proposal addresses the issue of the meaning and scope of medicalisation through an analysis related to the field of pregnancy and geneticisation. From a methodological point of view, it combines a conceptual approach with a case-study analysis. It thus relates to an embedded way of practicing philosophy such as defined by A. Mol and D. Dickenson.

The consideration according to which medicalisation is an increasing trend in Western contemporary society has become a commonplace. However, its meaning and its actual scope are far from obvious. This proposal is a contribution to clarify them on the basis of a specific example.

It examines the reasons for which, in France, there are legally two ways to terminate pregnancy since 1975: one is associated to personal reasons, the other is grounded on "medical" criteria. It could be viewed as one of the many examples of such medicalisation. But is it?

In this specific case, the institutional organisation of the medical termination of pregnancy exemplifies a complex arrangement in which both the medical team and the couple play a part. The law is formulated to allow significant variations in the way decisions are made. Consequently, according to the more or less "liberal" culture of the unit, the decision to

terminate a pregnancy for medical reasons may include elements that ambiguously fuel a process of medicalisation.

In this matter, the interpretative hypothesis we would like to present about “medicalisation” is the following: it may be that decisions are made on the basis of “medical” criteria. However, considering how medical practice is both penetrated by extra-medical values and claims for the respect of the autonomy of the patients and reshaped through the criticism of paternalism, these so-called “medical” criteria include non-medical considerations. In other words, in some societies and legal systems, the new ethical collective trend contributes to mix medical and extra-medical criteria. As a consequence, the process of medicalisation cannot be considered as a “pure” one, but as a locus of encounter between these two types of criteria and a process with blurred outlines.

We will illustrate this hypothesis with the results of a study led between 2011 and 2014 with the method of clinical ethics such as developed by the Centre d'éthique Clinique of Cochin Hospital. This study examines the reasons formulated to ground a medical termination of pregnancy once a prenatal diagnosis has revealed a genetic disease, with or without certainty. It reveals the taking into account of reasons that are linked to the “balance” and integrity of the individual, the couple, the siblings and the family at large, as much as to the “quality of life” of the future child. Through this example, we will also reflect on the relationship between medicalization and geneticisation.

Euthanasia in persons with severe dementia

Gastmans, Chris

Chris.Gastmans@med.kuleuven.be

The number of people suffering from dementia will rise considerably in the years to come. This will have important implications for society. People suffering from dementia have to rely on relatives and professional caregivers when their disorder progresses. This provokes a feeling of being vulnerable in the people concerned. Some people want to determine for themselves their moment of death, if they should become demented. They think that the decline in personality and the vulnerability caused by severe dementia is shocking and unacceptable. In this context, some people consider euthanasia as a way to avoid total deterioration and vulnerability. Euthanasia of persons with dementia is allowed by the Belgian Act on Euthanasia as long as the person still has the required competency to express his actual euthanasia request. However, euthanasia of persons with severe dementia, as decreed in an advance euthanasia directive (AED), is not allowed in Belgium. Bills have been put forward in the Belgian Parliament to extend the current Act on Euthanasia towards persons suffering from severe dementia. In this contribution, we discuss some ethical and practical dilemmas regarding euthanasia in persons with severe dementia based on advance euthanasia directives. The main question is: Are advance euthanasia directives (AED) to be considered as dignity-enhancing care instruments to overcome the vulnerability of persons with severe dementia. Two main approaches to AED will be discussed: The principlist oriented or the ‘precedent autonomy’ approach on the one hand and the relational care oriented or ‘experiential interest’ approach on the other hand. We conclude our contribution with a critical ethical evaluation of euthanasia care practices in persons with severe dementia.

New clinical trials regulation: Another sign of pharmaceuticalisation?

Gefenas, Eugenijus

eugenijus.gefenas@mf.vu.lt

A recent adoption of the new Clinical Trials Regulation (CTR) by the European Parliament which will become applicable after May 2016 and therefore will replace the EU Directive 2001/20/EC on Clinical Drug Trials has sparked a very intensive public debate about the consequences of changing international regulations. Worries have been raised from the very beginning of the public consultation procedure that the CTR will reduce the role of research ethics committees and therefore will weaken protection of study participants. On the other hand, as has been stated in the Explanatory memorandum to the CTR, the existing provisions of the Directive 2001/20/EC appear to have hampered the conduct of clinical trials in Europe, therefore the aim of the new Regulation is to make it easier to conduct multinational clinical trials and to restore the EU's competitiveness in clinical research and the development of new and innovative treatments and medicines. It becomes clear from this short description of the issues raised during the public debate that the adoption of the new regulatory framework for clinical drug trials reflects some key features of the so-called pharmaceuticalisation discourse. In this context, it is important to emphasize that the amendments of the international regulatory framework might be seen as a manifestation of the changing relationship between regulatory agencies and pharmaceutical industry which is according to some medical sociologists an important component of the pharmaceuticalisation. Therefore, in this paper different aspects of changing forms of governance relevant to the pharmaceuticalisation, such as increased dependency of regulatory agencies on industry as well as globalisation of established models of governance based on the interests of the pharmaceutical industry will be further analysed paying particular attention to the role the new document assigns to the research ethics committees.

Self- and other-enhancement. Humanism with new means?

Gelhaus, Petra

gelhaus@ukmuenster.de

By the example of ADHS (Attention Deficit and Hyperactivity Syndrome) and its medication with central stimulants, I want to problematize the borderlines between disease, social requirements and personal optimization.

My focus is not the well-known critique about the strong social contamination of the diagnosis of ADHS, but on the contrary a critical view to the classical humanistic program of education and self-education in analogy to the deficit-focussed view of development that an healthcare-inspired perspective suggests. Which ideal shall we try to approach? We cannot strive for a general level of normality, can we? What about an individual normality? Or an individual ideal as implicit in humanistic values? However, if we can (only) reach these goals with pharmacological means, why should this be worse than using training, education, and personal struggle?

In this paper I want to discuss these questions and give arguments for making a distinction between disease and enhancement as clear as possible, as well as a distinction between public and individual demands on personal development and performance, which should inform the delicate decision if one may/ought to use pharmacological means in order to improve.

A critique of the biomedical conception of truth

Gerber, Berna

berna@sun.ac.za

Communication between doctors and patients in clinical settings is notorious for being difficult. I will argue that biomedicine's natural scientific conception of truth may create many of the problems in clinical interactions and may result in poor patient outcomes. To do this I will make comments about doctor-patient communication (as it is described in a vast empirical research literature) based on Jürgen Habermas' (1979) universal pragmatics. The argument can be summarised as follows:

Doctors and patients communicate from different perspectives. The doctor's professional perspective is turned to the world of external nature. (S)he mostly communicates in the cognitive mode of language use. The patient mostly communicates about his/her world of internal nature in the expressive mode of communication. Due to their different perspectives, doctors and patients may not accept the validity claims that underlie each other's utterances about the nature, causes and treatment of disease. When either member of a doctor-patient dyad does not accept the validity claim(s) implicit in the other's speech act(s), their "communicative interaction can break down or suffer disturbances" (McCarthy, 1978:288) and they will fail to reach agreement through communication. The different perspectives of the doctor and patient are not necessarily problematic, as in the case of consultations regarding single acute physical conditions. However, it often causes (mostly covert) disagreement in consultations regarding chronic disorders.

The 'true' statements of medical discourse are about the material aspects of reality. The biomedical understanding of the concept of truth is concerned with a characteristic of certain statements. Truth refers to the correctness and precision of these statements. These statements are regarded as correct because they refer to facts that were determined through stable and scientifically established procedures and therefore can be verified by anyone with the necessary expertise (Rossouw, 1982:102). The true statements of medical discourse precisely signal "the 'natural' order of human biology" (Good & Good, 1981:179). The question is whether this narrow, scientific understanding of truth is appropriate for the context of clinical medicine? And if not, what would an appropriate conception of truth be for medical practice? In response to the first question and in the light of my argument that medicine's positivist world-view negatively influences clinical communication and consequently the quality of clinical medicine, I answer 'no'. In response to the second question, Hennie Rossouw (1982) provides a rich, quite poetic and very useful conceptualisation of truth for the context of communication between a doctor and a patient. I shall reconstruct Rossouw's argument and shall then critique modern medicine's understanding of truth in the light of Rossouw's description of an appropriate concept of truth for clinical medicine.

References:

- Good, B.J. & Good, M.D.V. 1981. 'The semantics of medical discourse', in: Mendelsohn, E. & Elkana, Y. (eds.). *Sciences and Cultures. Anthropological and Historical Studies of the Sciences*. Dordrecht: D Reidel Publishing Company. pp. 177-212.
- Habermas, J. 1979. *Communication and the evolution of society*. London: Heinemann Educational Books Ltd.
- McCarthy, T. 1987. 'Introduction', in: Habermas, J. *The Philosophical Discourse of Modernity: Twelve Lectures*. Cambridge: M.I.T. Press. pp. vii-xvii.
- Rossouw, H.W. 1982. 'Waarheid en siekte', in: De Villiers, D.W. & Anthonissen, J.A.S. (eds.). *Dominee en Dokter by die Siekbed*. Kaapstad : N.G. Kerk-Uitgewers. pp. 97-107.

Medicalization and positional shifts between sociologists, medical doctors and bioethicists

Gjernes, Trude

Trude.Gjernes@uin.no

Professional discourse on medicalization originated in sociology, based on a critical gaze on the medical profession's role in society. More recent analyses have acknowledged that medicalization is a more complex phenomenon, wherein the medical profession is only one of many actors. Among recent theoretizations are also the claim that medicalization has been replaced by biomedicalization. In these analyses there seems to be a shift from a critical gaze towards a more neutral way of studying medicalization. To examine this apparent shift in the sociological analyses of medicalization will thus be a major aim of this presentation.

Medicalization theory can also be seen as one of the most influential contributions of the sociology of health and illness, as it has been widely adopted by scholars outside sociology. Among the more notable adoptions are the ones stemming from within the medical profession, as illustrated by the recent focus on overdiagnosis. Although less theoretically focused, this adoption has seemingly kept the original critical focus on medicalization. The second aim of this presentation is to examine these adoptions, with a particular focus on whether

Another recent addition to the professional discourse on medicalization has also come from the ranks of bioethicists, presenting themselves as aiming for more of a balancing act between what is presented as the good and the bad sides of medicalization. As a more recent addition to the medicalization discourse, it may not be representing a positional shift as such. The last aim of this presentation is thus an examination of this more recent position, and also to identify similarities and differences between the various professional actors that are presently engaging the challenges of medicalization.

Early detection of primary thyroid cancer in children. A cost-effectiveness analysis to assess repetitive diagnostic tests, interventions and parents' overstress. A call for a new disease classification

Grossi, Armando; Rosati, Paola

paola.rosati@opbg.net

Background: Over the past three decades awareness and burgeoning screening tests have overemphasized cancer diagnosis also in children, thus increasingly detecting at an early stage non lethal cancer lesions, namely indolent lesions of epithelial origin (IDLE). Because the term IDLE, introduced by Esserman et al. in 2009, is still missing from the International Classification of Diseases (ICD-10), physicians tend to order unnecessary tests and interventions thus overstressing children and their parents. When a child's cancer is first suspected, definitive histological diagnosis is needed to ascertain whether the tumour type is life-threatening. In thyroid cancer specifying early whether a lesion is histologically non lethal will minimise the compulsion for repeating stressful imaging, and painful procedures.

Aim of the study and outcome measured: To analyse costs and consequences, and alternative therapeutic options that might reduce stressful and expensive procedures after the diagnosis of thyroid cancers, we reviewed the diagnostic and therapeutic work-up of a cohort of 23 children with primary thyroid cancer during a 20-year follow-up (1993-2014) at Bambino Gesù Children's Hospital. Primary outcome measures were the type of cancer lesions, mortality, and diagnostic and therapeutic interventions and procedures.

Method: In this cost-effectiveness study we included all children 0-17 years diagnosed for primary thyroid cancer in our hospital (1993-2014). Children whose parents were of non-Italian ethnical origin, children with a secondary thyroid cancer and children whose follow-up failed to identify histological findings of cancer lesions were excluded. We assessed 10 variables (number and type of histological cancer lesions, deaths, number of imaging tests, surgical interventions, outpatients and inpatients scheduled and unscheduled visits and admissions, and type of cancer classified (ICD-10) at discharge). In a comparative analysis of cost estimates to assess the risk-benefit of a watchful-waiting protocol, we used alternative scenarios based on scheduling three variables (imaging, surgical interventions and admissions) to reduce overstress (unscheduled visits/admissions), and procedures.

Results: In this paper we present our preliminary results. The age at the diagnosis of thyroid cancer was 4.3 years \pm 1.5 SD (range 2.8 – 5.8). Of the 23 children studied, two children died at 4 years after the diagnosis for diagnoses other than thyroid cancer (one accident, one leukaemia). None had a histologic finding of lethal thyroid cancer (medullary or anaplastic carcinoma). All these 23 children underwent surgery followed by regular postoperative surveillance including repeated imaging, outpatients and inpatients visits and admission. In all 23 children a IDLE was histologically confirmed (5 had follicular and 18 papillary carcinoma) and papillary or follicular thyroid carcinoma was written at discharge (ICD-10). At the conference we will present the complete cost-effectiveness analysis and comparative analysis of cost estimates, obtained by assessing changes in the various risk and benefit procedural scenarios after applying a watchful-waiting protocol.

Conclusions: To resolve problems related to overdiagnosis and overtreatment in thyroid IDLE hence reducing children and parental overstress and decreasing economic costs, we need to modify the current cancer paediatric classification and establish a new registry for children with IDLE who might be better treated with a watchful-waiting therapeutic/management approach.

References:

Esserman L, Shieh Y, Thompson I. Rethinking screening for breast cancer and prostate cancer. *JAMA*. 2009;302(15):1685-1692.

Committee on a Framework for Development of a New Taxonomy of Disease; National Research Council. *Toward Precision Medicine: Building a Knowledge Network for Biomedical Research and a New Taxonomy of Disease*. Washington, DC: National Academies Press; 2011.

CoonER, QuinonezRA, Moyer VA, SchroederAR. Overdiagnosis: how our compulsion for diagnosis may be harming children. *Pediatrics*. 2014 Nov;134(5):1013-23. doi: 10.1542/peds.2014-1778. Epub 2014 Oct.

Jenks S. Downgrading cancer definitions: overdiagnosis fuels the discussion. *J Natl Cancer Inst*. 2014 Mar;106(3):dju070. doi: 10.1093/jnci/dju070. Epub 2014 Mar 7.

BritoJP, MorrisJC, MontoriVM. Thyroid cancer: zealous imaging has increased detection and treatment of low risk tumours. *BMJ*. 2013 Aug 27;347:f4706. doi: 10.1136/bmj.f4706.

Too little sex? The pharmaceuticalisation of female sexual interest disorder

Grunt-Mejer, Katarzyna; Chańska, Weronika

kgruntmejer@gmail.com

We will present a multi-dimensional analysis of the process of constituting of Female Sexual Interest Disorder across consecutive editions of Diagnostic and Statistical Manual of Mental Disorders (including the latest DSM V). This comparative historical research aims to

reconstruct the changing sexual norm hidden behind the alleged scientific criteria. We will also address ethical implications of defining sexual variety in the terms of dysfunction.

The history of defining the aforementioned sexual dysfunction demonstrates that for a long time the discourse regarding normalcy of sexual functioning has been dominated by two conflicting approaches: the biological model of human sexuality and psychoanalytic assumption of an ideal female sexual reactivity. Both have been widely criticized by social constructionists and feminist activists as inappropriately based on the male model of sexual functioning or too immersed in cultural norms regarding female sexuality. The approaches have been also accused of ignoring the plethora of socio-psychological factors underpinning female desire.

In the dawn of the DSM-IV a new tactic of defining female decreased sexual interest was invented. The traditional way of defining dysfunctions – starting from symptoms and leading to the search for treatment – was reversed. The success of Viagra paved the way for inventing disorders that could be “cured” by a pill. The search was started to invent a female dysfunction that would become a counterpart of male erection problems. The process of pharmaceuticalisation – that is the transformation of human conditions into opportunities for pharmacological interventions – was started. It posed new ethical problems and challenges: Who is the beneficiary of the diagnosis? How does the pharmaceuticalisation ignore the psychosocial roots of the “problem” and stymie its adequate solving? And what other problems does it raise – concerning authenticity, freedom and choice? Our analysis will aim at mapping the aforementioned problems and associated ethical implications.

Medicalisation and manipulating morality

Gunson, Darryl

darryl.gunson@uws.ac.uk

In 2008 Persson and Savulescu published a paper arguing that research into cognitive enhancements (CE) should be accompanied by research into moral enhancement (ME).¹⁵ The implication was that when the products of the research into CE are available, people should be required to undergo ME because significantly increased cognitive powers in the population poses a threat to human well-being, and ultimately to our survival. This, it was argued, is because of the increased numbers of people who would be able to manufacture weapons, devices, or substances, that could kill large numbers of people. The debate has moved on somewhat since 2008, but in some ways it has not. A similar argument also forms part of their defence of ME in a paper from 2010.¹⁶ In this presentation I discuss how the proposal to ‘enhance morality’, using drugs or genetic techniques, is a striking example of ‘medicalization’ – of treating a social problem as though it were medical.

The paper does not promote a general argument against medicalization, but it does take issue with this particular instance. First, different models of morality and moral agency are outlined before arguing that the discussion of ‘enhancing morality’ is only defensible from one of these perspectives. It is argued that their assumed perspective leaves insufficient room for moral deliberation and the possibility of people doing other than they actually do. The supposed justification does not work because the ethically dubious project of ME is

¹⁵ I. Persson, J. Savulescu. (2008) ‘The Perils of Cognitive Enhancement and the Urgent Imperative to Enhance the Moral Character of Humanity.’ *J Appl Philos*; **25**(3): 162-77.

¹⁶ Persson, I. and J. Savulescu (2010). "Moral Transhumanism." *Journal of Medicine and Philosophy* **35**(6): 656-669.

supported by the promise that it is required to prevent people from harming others, when, it is argued, this is not always a requirement of morality.

It could always be replied that their version of morality is a form of consequentialism. As such, if it could be guaranteed that compulsory ME would have the consequence of preventing future killing of large numbers of people, then perhaps it would be justified. However, given that no guarantee of this effect could be forthcoming, the imagined project of compulsory ME is not justified, even on consequentialist grounds. The paper supports this conclusion by exploring how evidence from situationist ethics and moral psychology casts doubt on the idea that enhancement by genetic or pharmacological manipulation of the causal bases of our moral dispositions – brain chemistry – would be effective in changing moral behaviour in the desired way. Thus, this proposal is likely to be ineffective because there is strong evidence to suggest that our moral behaviour is highly sensitive to differences in social context. The emphasis should, it is argued, be placed on the manipulation of the social environments in which people form their moral views, which is not deterministic, rather than on their brain chemistry. Thus, in this particular case, the example of medicalization is both immoral and practically ineffective.

A Gift for Life? Exploring bodily sharing and kinship in live uterus transplantation between relatives and friends

Guntram, Lisa

lisa.guntram@liu.se

Absolute uterine factor-infertility – the absence or malfunction of the uterus – is the only major type of female infertility still considered untreatable. However, in the fall of 2012 nine women diagnosed with uterine-factor infertility took part in the world's first uterus transplantations involving live donors, at Sahlgrenska University Hospital, Sweden. These uterus transplantations were also, in contrast to the two previous post-mortem uterus transplantations (Erman Akar et al., 2013; Fageeh et al., 2002), the first using donors related to or friends of the recipients. In 2014, seven of the recipients had had embryos inserted into the transplanted uterus and the same year the first baby was born as a result of the treatment (Brännström et al., n.d.).

Uterus donation is, in contrast to other forms of live organ donation, not crucial to the recipient's survival but meant to enable the recipient to experience pregnancy (Brännström et al., n.d.). Furthermore, the practice entails that the intended child will have 'shared' the same uterus as the children of the donor. To give a few examples, this means that if the recipient receives a uterus from her mother she may have the same uterus that she herself was conceived in inserted into her body and the intended child may come to 'share' the same uterus as its mother. If the donor is a friend of the recipient the intended child will come to share the same space as the friend's children. And, if the donor is the mother-in-law of the recipient the intended child may come to share the same bodily space as its father.

How may these features live uterus transplantation between relatives or friends shed new light on the sharing of body parts and bodily spaces? And, that new interpretations of relationality and kinship may this practice bring to the fore?

Against a backdrop of feminist phenomenological perspectives on medicine and relationality (e.g. Käll and Zeiler, 2014) and feminist studies of how sociocultural norms are enacted in assisted reproductive technologies (ART) (e.g. Franklin, 2013; Thompson, 2005) I aim to address these questions in an attempt to tease new dimensions of inquiry and new challenges that this medical innovation bring to the field of ART. Lisa Guntram ESPMH 2015

References;

Brännström M, Johannesson L, Bokström H, et al. (n.d.) Livebirth after uterus transplantation. *The Lancet*, Available from: <http://www.sciencedirect.com/science/article/pii/S0140673614617281> (accessed 7 October 2014).

Erman Akar M, Ozkan Omer, Aydinuraz B, et al. (2013) Clinical pregnancy after uterus transplantation. *Fertility and Sterility*, 100(5), 1358–1363.

Fageeh W, Raffa H, Jabbad H, et al. (2002) Transplantation of the human uterus. *International Journal of Gynecology & Obstetrics*, 76(3), 245–251.

Franklin S (2013) *Biological Relatives - IVF, Stem Cells and the Future of Kinship*. Duke University Press.

Käll LF and Zeiler K (2014) *Feminist Phenomenology and Medicine*. Albany: SUNT Press.

Thompson C (2005) *Making Parents: The Ontological Choreography of Reproductive Technologies*. Cambridge, MA: MIT Press.

Attempts to medicalise personality differences and their wrongness: The case of introversion

Häyry, Matti

matti.hayry@aalto.fi

This paper focuses on the discrimination of introverts in a world dominated by extraverts. Academic psychology regards introversion as a neutral category, indicating that some people have more inward-directed features than others. The neutrality is the same whether the basis of introversion is thought to be psychological, physiological, or genetic.

In contrast with this non-pathological reading, two influential psychiatric classifications of mental diseases and disorders include, or have come close to including, introversion in their lists.

The *Diagnostic and Statistical Manual of Mental Disorders* (DSM), published by the American Psychiatric Association (APA) since 1952, is an authoritative source for clinicians, insurers, drug companies, lawmakers, and public decision makers in the United States.¹⁷

When the latest edition was being prepared in 2010, the need for including introversion as a constituent element of certain disorders was seriously considered.¹⁸ The proposal was eventually withdrawn, but the fact that it was made in the first place indicates that extraversion is seen in some quarters as the normal and healthy human condition, while introversion, at least in some of its forms, can be regarded as pathological.¹⁹

The *International Statistical Classification of Diseases and Related Health Problems* (ICD) by the World Health Organization (WHO) has followed, with some delay, the DSM guidelines in the categorisation of mental disorders. In ICD 9, widely in use until 1996, introversion was included in relation to schizoid personality disorders: class 301.21 “Introverted personality” was described alongside with other mental ailments.²⁰ Although the category has since then been dropped, previous lists are still employed, and the suggestion that introversion is something to be shunned probably lingers on in people’s minds.

The definition of introversion as a disorder, combined with the idea that it is genetically determined, would lead some bioethicists to propose the prenatal elimination of children who could be afflicted. Julian Savulescu has suggested that “[parents] should select the child, of the possible children they can have, who is expected to have the best life, or at least as good a

¹⁷ www.psychiatry.org/practice/dsm

¹⁸ Nancy Ancowitz, “A giant step backward for introverts”, *Psychology Today*, 6 August, 2010.

¹⁹ Nancy Ancowitz, “APA gains sanity: Introverts not nuts”, *Psychology Today*, 6 June 2012.

²⁰ www.assessmentpsychology.com/icd9cm.htm

life as the others, based on the relevant, available information.”²¹ This “principle of procreative beneficence” implies, according to Savulescu, that prenatal diagnoses should always be used as a basis of selecting our offspring; and that in making our reproductive decisions we should never knowingly choose a child with a disease, disability, or disorder, if children without them are easily available. This, in its turn, means that if introversion is defined as a disorder and if parents can choose between an introverted and an extraverted future child, they should indisputably go for the latter. This paper explores these ideas and their legitimacy further.

The Imperative of the Unknown: Caring for extreme preterm infants

Hendriks, Manya J; Streuli, Jürg C

manya.hendriks@usz.ch

Since the beginning of the eleventh century human kind has focused on the pursuit of improvement and, specifically, technological change. Over the years, the impact of biomedical technology and its advancement on our bodies has taken many forms. In general, the development of medicine involves the care for the sick aimed at alleviation and cure.

In the field of neonatology it seems that medical technology is not solely aimed at regaining health. Since the late 1960s, technological advancement and innovation has improved patient survival. These improvements are often described as ‘miracles’ of the late twentieth century technology. For example, current advances in neonatal care allow more extremely low gestational age (ELGA) infants of <28 weeks to survive. This specific group of newborns, born at the limit of viability, owe their lives to medical technology. Hence, the goal of medical technology in caring for ELGA infants is dedicated to give these children a chance to live rather than curing an illness.

Today more extreme preterm infants survive than ever before due to technological improvements. However, these children remain to be at higher risk for disabilities. Furthermore, it is very difficult to predict treatment and future outcomes for ELGA infants. As a consequence this has brought to existence new ethical challenges. First, letting the (medical) facts speak for themselves is not an option due to prognostic uncertainty. Second, it is very difficult to establish when enough is enough. It can be challenging to identify futility or overtreatment. For instance, when the likely outcome is poor but the degree of severity is uncertain. Third, personal values and attitudes come into play when assessing the best-interest of the child. For example, physicians who apply more extensive treatments can consider this as the right thing to do. But other physicians might regard this type of treatment as medically futile and, as such, more problematic than undertreatment. This results into diverse ethical and moral evaluations of appropriateness for care. Along these lines, decision-making for withholding or withdrawing of treatment can become more ambiguous. As a result, these challenges complicate end-of-life decision-making for family members and health care professionals.

Our hypothesis is that medical technology is value-neutral and it is the *application* of technology that requires an ethical evaluation. This article will review the literature on technological improvements in the field of ELGA infants and examines the moral attitude of stakeholders toward these advancements. It is important with changing technology to constantly re-evaluate the indication to use certain medical techniques. The danger of the imperative of the unknown (i.e. uncertainty) is pursuing all available medical options. Instead

²¹ Julian Savulescu, “Procreative beneficence: Why we should select the best children”, *Bioethics* 15 (2001): 413-426, p. 415.

we argue that appropriateness of care should be based on the pursuit of a balanced decision. And especially, focus on the positive consequences of technological advancement alongside a well-established ethical evaluation.

Autism Spectrum Disorder: Genetics and Ethics

Hens, Kristien

Kristien.Hens@kuleuven.be

Much has been researched on the origins of autism spectrum disorder (ASD). Many studies investigate the relation between genetic variation and the autistic phenotype. Also epigenetics is thought to be especially promising as a mechanism to explain the development of the phenotype. Despite the huge volume of papers on the science of autism genetics, there is relatively little research on the ethics of ASD. However, given the specific status of autism as a spectrum disorder (from a disability to a difference), ethical reflection is urgently needed. For example what should be the aim of fundamental genetic research on autism genes, prevention or better clinical care? Are research subjects with autism to be considered more vulnerable than controls without autism? What issues arise in genetic counseling of families with autistic children? I interviewed 16 professionals (education specialists, psychologists, psychiatrists and neurologists) on the topics of genetic research, genetic counseling and reproductive choice. In this talk I present the results of this interview study and I discuss conflicting opinions. I point out that, in order to sufficiently answer certain ethical questions regarding autism research, underlying assumptions regarding the nature of the condition and the desirability of prevention or cure need to be explored first.

Medicalization and overdiagnosis – same and different?

Hofmann, Bjørn

bjorn.hofmann@medisin.uio.no

Medicalization is frequently defined as a process by which some aspects of human life that were not previously considered so come to be considered as medical problems. Overdiagnosis, on the other hand is frequently defined as the detection of a disease that in the absence of testing would not have been diagnosed in the person's lifetime. Medicalization and overdiagnosis are related as they normatively are often considered to be futile and even harmful. Both medicalization and overdiagnosis increase the number of persons who are diseased, or more strongly: they make more people diseased. By making persons who were previously not considered to be diseased, diseased, overdiagnosis can contribute to the process of medicalization. However, there are important differences between the concepts, as not all cases of overdiagnosis are medicalizations and not all cases of medicalizations are overdiagnosis. This presentation will clarify the differences between medicalization and overdiagnosis. It will demonstrate how medicalization and overdiagnosis traditionally had different ties to social and cultural processes on the one hand and biological processes on the other hand. However, this is changing, which may have significant implications for how we think about medicine in the future.

Is second order nudging ethically acceptable?

Holm, Søren

soren.holm@manchester.ac.uk

This paper will discuss if second order nudging, i.e. the nudging of politicians by health researchers / professionals to try to obtain better health policies, is ever ethically acceptable.

The first part of the paper will define second order nudging and give some examples where it has occurred.

The second part will, for the sake of argument accept libertarian paternalism as the justification for ordinary, first order nudging of the population by public health officials, and will analyse whether and under what circumstances this justification can be extended to second order nudging. It will be argued that although second order nudging is more problematic than first order nudging, because of the respective roles of politicians and health researchers / professionals in a democratic society, there may be circumstances in which second order nudging is acceptable.

The final part will then briefly discuss whether health researchers / professionals are well placed to judge for themselves when second order nudging is acceptable, and will argue that there are many situations where they are not well placed to decide this for themselves.

Nudging: what ethical arguments are going round?

Hoven, Mariëtte van den; Vugts, Anastasia

M.a.vandenhoven@uu.nl

The idea of nudging has become popular in (political) debates and governance. Several BIT teams have been established in countries like the UK and the United States that aim to stimulate specific effective interventions that steer people's behavior. The idea that you can steer people's behavior towards a better and healthier life, to more welfare and well-being, is very attractive. At the same time philosophers and ethicists have raised important considerations that should be taken into account. If a nudge is steering the unconscious, irrational behavior of agents, this could be problematic when it infringes or bypasses their autonomous choices (White, 2013). The fact that people behave irrational is not a justificatory reason to simply bypass considerate choice whatsoever! At the same time, some have suggested that nudges might stimulate to become more autonomous: they could empower agents to be who they want to be; to live up to their goals and life values (Mills, 2012). Ashcroft points out that not only the mechanisms of nudging, but also the question who can nudge and what nudges seem acceptable is open for philosophical debate (Ashcroft, 2013). Does it matter whether a company steers your choices as a consumer, or that a government nudges you? And does it matter whether the nudge regards your food choices, organ donation or pension options? As part of a broader project on the effectiveness, feasibility and legitimacy of nudging (WINK project), we decided that an overview of arguments used so far would be helpful. Not only to find out how often ethical arguments are used in the debate, but also what type of arguments are brought to the fore.

Method: We selected journal articles via Scopus and Google Scholar and selected those articles that present arguments in the debate on the acceptability and legitimacy of nudging. We narrowed the number of articles using the keywords of the articles that could indicate an ethical or philosophical perspective on the debate. A first selection narrowed down to 55 articles in Zotero, which we further labeled with keywords based on the abstracts of the articles. Then the arguments in the articles were analyzed using a qualitative methodology (coding) in Atlas ti and we further analyzed its contents. The result is an overview of the

quantity and variety of arguments used so far, as well as a substantial review of the content of these arguments. How well developed are these arguments? In this presentation we will bring present the results of this review of the debate in the literature.

References:

Ashcroft, R. (2013). Doing good by stealth: comments on 'Salvaging the concept of nudge'. *Journal of Medical Ethics* 39(8): 494.

White, M.D. (2013). *The Manipulation of Choice. Ethics and Libertarian Paternalism*. New York: Palgrave Macmillan.

Mills, C. (2012). Why Nudges Matter: a Reply to Goodwin. *Politics* 33(1): 28-36.

Women's agency in the use of reproductive technologies - An updated feminist critique of medicalisation

Huebel, Sylvia

sylviahuebel@gmail.com

Medical sociologists and feminist scholars tackled the process through which involuntary childlessness has shifted from the social realm to the medical one. They argued that the availability of new reproductive technologies and the increasingly restrictive definitions of infertility played a major role in shaping women's perceptions and their treatment-seeking behaviours. At their outset, both the feminist as well the sociological critique focused on the medical profession and institution as the prime movers of medicalisation. However, by the 1990s, the situation has significantly changed, and the critics called the attention to the emergence of a plethora of new political and economical "engines" of medicalisation. Biotechnology, the pharmaceutical industry, healthcare systems and insurance plans, free market ideology, and consumers themselves have all become the driving forces of assisted reproduction. We have witnessed a shift in the cultural understanding of the patient from a passive figure or a receiver of care to that of an empowered agent and a consumer of fertility treatments.

Feminist ethical scholarship focused for long decennia on the concerns regarding the commodification of women's bodies and reproductive capacities and the tensions inherent in the process of medicalisation. Being a patient was perceived as a reduction of the body to an object of scrutiny and medical intervention. We wish to problematize the earlier feminist critiques as they obscure the complexity of the lived experience, and they do not acknowledge women's increased control in the use of reproductive technologies. Nowadays, women assume a more assertive role in fertility treatments. There is an evident shift in the way, how they renegotiate the frontiers of their body, their corporeal subjectivity and agency in the treatment process. They are active agents in defining their own experience and claiming their embodied knowledge. They develop counter-narratives to the dominant discourses, and they construct new conceptions of motherhood. As an illustration, we will dwell on some of the new manifestations of patient agency during fertility treatments. For instance, we will refer to the emergence of online groups as sites of patient empowerment. We will argue that the internet has become a tool of empowerment, allowing patients access not only to medical knowledge and information, but even more importantly to peer support.

This very complex reality challenges feminist bioethicists to revisit their critiques of medicalisation. Any ethical intervention would be difficult, if not impossible, without a full understanding of the new manifestations of patients' agency and their interplay with the "engines" of medicalisation.

Neurodiversity and the medicalisation of autism

Hughes, Jonathan

j.a.hughes@keele.ac.uk

Debates about ethical questions relating to autism are often polarised between a broadly medical approach, common among practitioners, researchers, and parents of autistic children, and the neurodiversity perspective taken by many autistic people themselves. This can be seen, for example, in arguments about research into the causes of autism, screening and prevention, and interventions aimed at curing autism or normalising autistic behaviours. The concept of neurodiversity has been analysed in various ways, for example in terms of its answers to these practical-ethical questions, by analogy with struggles against racial, sexual and other forms of discrimination, and as a rejection of the characterisation of autism as a disorder or disability. In this paper I start by postulating that neurodiversity can be understood as a protest against the medicalisation of autism, and examine the implications of this analysis.

In order to do this I will consider what it means to treat a condition like autism as a medical phenomenon, the reasons for rejecting such a perspective, and whether such reasons support the degree of opposition to medicalisation that many neurodiversity advocates express. One complicating factor is that—as the term suggests—advocates of neurodiversity tend to emphasise the biological (and more specifically the neurological) basis of autism. In so doing they seem to embrace at least one aspect of a medical understanding of autism and to acknowledge that the results of biomedical research can be important for reasons that need not relate to controversial treatments. Consideration of the reasons for this biological focus may indicate other ways in which aspects of a medical approach can be of benefit to autistic people in ways that are consistent with the aims of neurodiversity.

These factors suggest that the medical and neurodiversity perspectives are (or should be) less mutually exclusive than the initial postulate implies. The approach to reconciling them taken by some theorists, of applying the neurodiversity approach only to those at the high-functioning end of the autistic spectrum, and the medical approach to those at the lower end, is problematic. While variation within the autistic spectrum is important, it does not lend itself to this simple division, and a satisfactory way of relating neurodiversity to medicalisation may also need to distinguish between different aspects of medicalisation and recognise that, as has been argued in relation to other bioethical issues such as disability and enhancement, the boundary between the medical and non-medical may not be as well-defined or significant as more polarised accounts might suggest.

Using deep-brain stimulation for Alzheimer's disease. Ethical and social implications

Ienca, Marcello; Jotterand, Fabrice; Elger Bernice

marcello.ienca@unibas.ch

Deep brain stimulation (DBS) is an approved and effective neurosurgical intervention for motor disorders such as Parkinson's disease and Essential Tremor. Recent unmet expectations in Alzheimer's disease (AD) pharmacological trials have indirectly promoted the application of DBS also to AD and Mild Cognitive Impairment, with the prospect of reversing cognitive decline mechanically rather than pharmacologically. At present, preliminary safety studies seem to corroborate the possibility of DBS-enabled modulation of neurophysiological activity in the pathological circuits and, consequently, possible clinical benefits. In the light of the increasing global incidence of AD -44.4 million people worldwide in 2013; set to increase to 135.5 million (1 in 85 people globally) by 2050- and the challenges

that this poses for public health and the health-care services, the potential benefits of applying DBS to AD are significant.

While DBS opens the prospect of a radically alternative avenue of AD research, it remains an invasive, expensive and ethically problematic procedure. For this reason, constant monitoring of the ethical, legal and social implications associated with its emerging therapeutic use in the context of dementia is required. Some of these issues are inherent to any application of DBS in psychiatry as they have been discussed in the medical and ethical literature. These include the problem of balancing therapeutic benefits and potentially associated risks, ensuring respect and protection for the autonomy of patients, predicting and monitoring the psychosocial impact of treatment with privileged attention on the effects on personal identity and personhood. Other issues may be peculiar to AD and cognitive decline. Through a review of the neurosurgical literature on DBS as well as the interdisciplinary bioethical and sociological literatures on AD, we identify and highlight some specific ethical and social challenges associated with the application of DBS to AD and dementia in general. We also distinguish the issues that are peculiar to the context of research from those of clinical practice. This review is aimed at producing an ethical framework to raise awareness over the emerging application of DBS to AD and taking a first step in developing recommendations that may maximize the possible clinical benefits of DBS while minimizing the risks.

Should autistic traits be medicalized or demedicalized?

Jaarsma, Pier

pier.jaarsma@liu.se

In the field of autism, medicalization as well as an attempt at demedicalization can be observed. On the one hand we have the neurodiversity movement that regards atypical neurological development as a normal human difference on par with e.g. homosexuality, and which aims at the demedicalization of some neurological disorders, among which Autism Spectrum Disorder (ASD). On the other hand we have (over)medicalization which can be detected in the ever growing number of individuals diagnosed with ASD (now 1 in 68 in the USA).¹ It has been suggested that ‘about half of the [autism] “epidemic” is probably service driven – children get the diagnosis incorrectly because it is the ticket to more attention in the school system and more intense mental health treatment (Frances, 2013, p. 147).’ Another instance of medicalization can be detected in recent autism research where the ‘Broader Autism Phenotype (BAP)’ is viewed as a social disorder that, according to the authors, would best be diagnosed by using biomarkers (de Jonge et al., 2014). Such medicalization inflates the number of individuals ‘suffering’ from autistic traits enormously, increasing stigmatization at the same rate. Assuming autistic traits to be part of normal human variation, consider the following argument about autistic traits and health: ‘natural human variations can either be good, neutral or bad for an individual’s health’, ‘natural human variations that are bad for an individual’s health should be medicalized’, ‘an autistic trait is bad for an individual’s health’ and the conclusion ‘autistic traits should be medicalized’. The problem with this argument is that autistic traits are *not* necessarily bad for an individual’s health. In an autistic-traits-friendly environment autistic traits can be neutral or even good for an individual’s health. As can be read in some autistic autobiographical reports, autistic traits may be beneficial to help the individual ‘realize all his or her vital goals given standard or reasonable circumstances (Nordenfelt, 2013, p. 280)’. In conclusion, the medicalization of autistic traits, as can be seen in the over-diagnosis of ASD and in the suggestion to diagnose BAP with biomarkers, is problematic because it results in unnecessary stigmatization of individuals. Therefore, along with the creation of autistic-traits-friendly environments,

responsible demedicalization of autistic traits, and relabeling these traits as neurodiversity, is necessary to eliminate and to prevent stigma for millions of people involved.

1 <http://www.cdc.gov/ncbddd/autism/facts.html> Accessed 27-02-2015.

References:

Frances, A. 2013. *Saving Normal: An Insider's Revolt Against Out-of-Control Psychiatric Diagnosis, DSM-5, Big Pharma, and the Medicalization of Ordinary Life*. New York: William Morrow (HarperCollins Publishers).

Jonge, de, M., Parr, J., Rutter, M., Wallace, S., Kemner, C., Bailey, A., Engeland, van, H., and A. Pickles. 2014. New Interview and Observation Measures of the Broader Autism Phenotype: Group Differentiation. *Journal of Autism and Developmental Disorders* DOI 10.1007/s10803-014-2230-7.

Nordenfelt, L. 2013. Standard circumstances and vital goals: comments on Venkatapuram's critique. *Bioethics* 27(5): 280-284.

Quaternary prevention (P4)

Jamoulle, Marc

marc_jamoulle@runbox.com

Quaternary prevention (P4), an answer of family doctors facing overmedicalization aims to protect the patient or population against the danger of medicine. Harmful effects can appear with preventive activities (example: prostate cancer screening by PSA) such as by therapeutic interventions (example: disruptive medicine). P4 promoted by the Wonca (World Organization of Family Doctors) is practiced in different ways around the world. The seminar should present examples of teaching and application of P4 in different countries. 4 short talks will be followed by an open roundtable about the philosophical aspects of P4, where the audience can participate. Asking the question: « is acting always justified in medicine? », P4 opens our thinking to a philosophy of action. Questioning the best way to reduce uncertainty, P4 is rooted in a philosophy of knowledge. How to decide action or abstention? How to appreciate the danger of both? How to accompany a patient without harmful effects (primum non nocere)? More about P4 on www.ph3c.org/p4

Curing, assisting, enhancing, altering: The emergence of recombinant technologies and the future of humanity

Jotterand, Fabrice, Ienca; Marcello; Elger, Bernice

fjotterand@regis.edu

The rapid progress of medical technology opens the prospects of impacting the lives of people in significant and, for many aspects unprecedented, ways. When reflecting on this emerging phenomenon, scholars tend to polarize the debate through the following three explanatory categories: therapy, assistance and enhancement.

Following Jotterand's reflection on enhancement and human nature (Jotterand, 2008), we suggest to introduce a fourth explanatory, namely the category of "alteration". Through this category we propose to describe a further dimension of the link between human life and technology, namely the dimension in which technology interventions are neither seen as restoring normality nor as enhancing normal function but as something that produces an *alteration* of the human life as such. We call this family of technology interventions *Recombinant Technology (RT)*. Taking a step from Kuhn's notion of "innovative change" in scientific revolutions and from Christiansen's notion of "disruptive technologies" we define

RTs as those technological artifacts that are neither designed for curing or compensating for lower-than-baseline functions nor for enhancing baseline functions but rather *create brand new functions* –hence significantly alter the nature of their users. A paradigmatic example of RT is brain-computer interfacing (BCI). BCI systems do not simply assist and support impaired users (e.g. patients suffering neuromuscular disorders), or enhance activities of normal users (e.g. more personalized user experience in gaming and entertainment). Most importantly, they create a function that would not otherwise be found in humans: the capacity of controlling an external computer device exclusively with brain activity, bypassing the peripheral nervous and muscle systems. Other examples of recombinant technologies are reproductive cloning, 3-parent IVF, ageing-reversal techniques, and mind uploading.

The term “recombinant technology” is borrowed from the notion of recombinant DNA molecule in molecular biology, which refers to artificially formed DNA molecules in which genetic material from multiple sources is brought together to create sequences that would not otherwise be found in biological organisms. In our analogy, RTs are artificially created applications where materials and codes are brought together from multiple sources to create functions (e.g., in the examples above, the creation of a genetically identical human being, 3-parent reproduction, unlimited life-span, and in-silicio replication of the human mind) that would not otherwise be found in humans.

The goal of this paper is threefold. First, we introduce and define the notions of recombinant technology and alteration. Second, we discuss what conceptual implications these notions have for the concept of humanity, i.e. for the self-understanding of our nature. If in the future the predicate “being a human” will also entail the reference to the capacity to control a computer solely by thinking and to produce an offspring with three genetic parents, what implications will this have on the semantics of the noun “humanity”? Third, at the normative level, we wish to discuss the ethical implications of recombinant technology and the major ethical issues surrounding the alteration of the human nature. These include problems of moral acceptability, limit-setting, access, misuse and global security.

Informing adolescents about their genetic information

Katzenelson, Edna

edna-k@013.net

Informing adolescents about their genetic information includes legal, psychological, medical and ethical questions. According to ethical principles, relaying genetic information especially true of adolescents in the midst of a sensitive stage of development, in which they have yet to reach the completion of cognitive, emotional and neurological development, must be based on the assumption that it will lead to more benefit than risk.

Genetic information includes a wide range of possibilities ranging from data with a high genetic probability, which is likely to help prevent a problem now, or information with a low genetic probability that may prevent moderate difficulties in the future.

Ethical considerations include whether a genetic test should be performed on minors in order to reassure concerned parents and to avoid placing limitations on the child as well as preventing unnecessary medical follow-up. It is reasonable to assume that relaying genetic information should be considered in an effort to help the adolescent adopt behavior that will prevent medical deterioration in the present or in the future. Relaying information to the adolescent relates to the issue of whether all genetic information should be considered part of the adolescent’s right to autonomy, or whether there is definitive information that should not be relayed to the minor. This includes information that cannot prevent the outbreak of the disease, but only facilitates psychological preparation for the future.

It is generally accepted that medical information and decision-making regarding treatment issues can be disclosed to someone defined as a mature minor. The people who determine whether the child is a mature minor are the child's parents, attending physician or a mental health professional.

The question also arises as to who is responsible for relaying this information - is it only the parent or also the doctor in possession of the information?

In addition, the adolescent's present situation must be taken into account - is he under unusual stress or in crisis, can support family systems and professional support framework, help him process the information.

I will present the family members as a part of the system of considerations that must be taken into account: The impact of relaying information regarding the parents, and other children in the family. Additionally, if the information is not relayed, we must consider whether the child will become angry at his parents for concealing the information.

The process of relaying the information must also be conducted following meticulous preparation, after ascertaining if and what the the adolescence wishes to know about the subject, in stages, and while relating to the information and the adolescent's understanding of the information and the emotional aspects it arouses.

I will suggest that the genetic information should not be seen as one unit. Rather, the various layers of the information should be identified; and consequently, the risk in revealing the information should be considered. I will present the circumstances in which adolescent should be informed and circumstances in which they should not be informed.

Consumer autonomy, or patient autonomy: Marketization of health services

Kekewich, Michael; Foreman, Thomas; Curran, Dorothyann

mkekewich@toh.on.ca

Through a number of sociomedical developments and reforms to health care systems, we have seen a change in the way patients have approached health care systems. The rise of the universal human rights movement, along with the many injustices that have occurred in the medical context in relatively recent history, has created an ideal space for rights and freedoms. In combination with various health care reforms, these changes have resulted in "consumers" approaching health services in the same way they would approach other marketplaces or commodities. In this context, conditions have been such that the view of individuals having the right to make autonomous decisions has become paramount, while the formerly paternalistic model has been more or less abandoned. Even the term "patient" seems to be less acceptable, as many health systems have adopted the term "client" or "consumer" as the most appropriate categorization of those seeking health care services. It can even be argued that the once negative right to informed consent originally established as a protection for patients has, in effect, grown features of a positive right to request services and receive accommodation. This transformation from negative to positive right ultimately supports a model of health care services where patients become consumers, or clients. This shift is further facilitated by the democratization of information through technology, with patients being able to access and understand information more easily than ever. As a result of patients self-educating in these ways, health care providers are at risk of being seen less as experts than technicians. Ultimately, this "market liberalism" gives rise to a dysfunctional view of consumer autonomy, which is very different from patient autonomy. The view is dysfunctional, because it's emphasis on choice doesn't adequately safeguard the interests of patients. In line with this movement toward greater patient autonomy and choice, many health care systems have also been under pressure to institute reforms aimed at increasing

efficiency, quality, and value for money. In many cases, these reforms have been instituted through increased competition within health care systems and a corresponding emphasis on greater patient choice. This has been described by some as a kind of neo-liberal "marketization" of health care services aimed at empowering users. In many cases, the effect of these reforms is a prioritization of autonomy via the operational principle of "choice". These two phenomena seem to complement one another nicely, but may also give rise to some fairly complex ethical issues. In particular, they appear to be changing the way in which health care is actually provided at some fundamental level. Patients are increasingly empowered (perhaps unreasonably), and organizations are expected to compete for their business, even in publicly funded systems. Ethically, are these appropriate objectives? Is marketization of services a morally sound means of transforming public services like health care? What impact does this commercialization have on the rights and responsibilities of organizations, providers, and patients?

Personalised medicine and the moral obligation to change

Kerasidou, Angeliki

angeliki.kerasidou@ethox.ox.ac.uk

Doctors and public health professionals are hoping that genetics will open the door to better and more effective disease prevention strategies. The expectation is that if people are aware of their risk factors for disease, they would take responsibility of the lifestyle and health choices and adopt changes that will improve their long term health outcomes. This way, '[p]reventing disease will also become the responsibility of the patient. He will know what the risks he takes if he smokes, over-eats or leads a sedentary life style. The risks will be personalized based on his own genetics' (Steakley, 2012).

It seems reasonable to assign personal responsibility to people for their actions. As long as the action is freely and autonomously chosen, one should not be acquitted of the cost of freedom that comes with being a free and autonomous agent. But is it possible to argue with certainty that health-related actions are always freely and autonomously chosen? And even if we can prove this, would it be fair if a national health system rewarded those who make the 'right' choices and penalised those who make the 'wrong' ones?

In this presentation am going to explore the notions of personal autonomy and responsibility within the context of personalised medicine and public health and will draw some conclusions on what this might mean for the national health system.

Commercialisation and genomic medicine

Kerasidou, Angeliki; Slade, Ingrid; Sheehan, Mark

angeliki@well.ox.ac.uk

The translation of genomics research from the laboratory into everyday medical practice is changing the way medicine is researched and applied. This research is expensive and within this context there has been increased partnership of the public sector and private companies with interest in genetic-related therapies and the technologies that accompany them. This might be taken as an opportunity to foster an increase in the commercialisation of healthcare development and delivery. Publicly funded health care systems simply cannot invest to the same degree in research and implementation pathways that industry can. It is clear that commercial support and resources will be required in order for the translation of genomic medicine to be realised.

At the same time, public attitudes and perception of the involvement of the pharmaceutical industry in genetics is, at best, hesitant. This scepticism is also true of many health care professionals. These attitudes are linked to and demonstrated by recent media attention associated with the disclosure of research data.²² In short, there seems to be a mismatch between the attitudes of the public towards markets and commercial interests in genomics research and what is required in terms of funding in order for the potential health outcomes of genomics to be realised.

The difficult and controversial cases of commercialisation involve a clash between the values of the market and the values of the practice into which the market is being introduced. Importantly these issues involve significant ethical and conceptual claims and presuppositions about the ethics of markets and the relationship between markets and other areas of value – specifically like the values that are significant in health and health care.^{23,24} It is precisely this clash and our understanding of it that forms the heart of the ethical issues concerning markets and commercial interests in healthcare generally and genomics more specifically.

This paper will attempt an ethical and conceptual analysis of public-private-partnerships in delivering genomic medicine within a publicly funded healthcare system. We will systematically critique the range of positions that might be taken on commercialisation and examine them in the context of genomic medicine. The ethical and conceptual positions will be tested in context for their ability to capture and account for the range of practical problems and solutions facing healthcare providers.

Ethics training for healthcare professionals working in the field of infectious disease control

Kessler, Carla; Rump, Babette

C.J.Kessler@uu.nl

Healthcare professionals who work in the field of infectious disease control are often confronted with ethical dilemmas. The classic problems are questions concerning quarantine, isolation and mandatory treatment, which are related to the underlying issue of individual liberty and autonomy versus public interests. In daily practice however, interventions as quarantine, isolation or mandatory treatment are hardly ever used. The ethical debate here concerns far less intrusive measures. Although the interventions used in daily practice are less intervenient, they nonetheless address the same issue of individual liberties and the common good. Daily practice may therefore also benefit from systematic ethical reflection.

Various tools have been developed for moral case deliberation in medical practice. The moral problems raised by daily practice of infectious disease control however extend beyond the ethical arena of medical ethics, where patient autonomy and informed consent are usually point of focus. Professionals working in the field of infectious diseases need to place their ethical reflection in the context of public health and the common good. The methods that are used for moral deliberation in medical ethics are therefore not always suitable for reflection in this specialized field.

In a collective project of The Ethics Institute of Utrecht University and the Municipal Health Service of the Middle Netherlands we have explored the variety of common moral problems

²² Goldacre, B. (2012) *Bad Pharma: How drug companies mislead doctors and harm patients*. London: Fourth Estate.

²³ Anderson, E. (1993) *Value in Ethics and Economics*. Cambridge, MA: Harvard University Press.

²⁴ Walsh, A. (2001) 'Are Market Norms and Intrinsic Valuation Mutually Exclusive?' *Australasian Journal of Philosophy*, Vol.79, No.4, pp. 525-543.

in infectious disease control. We have developed a method to analyse those problems and started an ethics training for teams of infectious disease control professionals to apply this method in moral case deliberation. We would like to present our experiences with the ethics training and show the method to analyse moral problems in the field of infectious disease control.

What makes medicalisation effective: Two case studies

Claire, Kim Junga

clairejungakim@gmail.com

Low birth rates have been a serious issue in Korea for some time. In an attempt to address this problem, the government implemented the National Program to Support Infertile Couples in 2006 to subsidise the fee for artificial insemination or *in vitro* fertilisation (IVF) to increase the total number of births. However, the program has achieved little success with regard to its aim of increasing the birth rate and securing a future working population. As a result, the program has been subject to criticism as an example of the uncritical introduction of medicalisation, due to a lack of understanding of the root causes of low birth rates. The current subsidisation of this artificial reproductive technology (ART) program is analogous to a previous program in Korea, the Family Planning Program, which was active from the 1960s to the 1980s to implement birth control policies. At that time, the program employed various methods to reduce the birth rate, from distributing condoms and educating people about them, to encouraging male/female sterilisation, and even abortion. The government considered the reduced birth rate as clear evidence for the success of this program. The current ART subsidy program is the same as the previous program with respect to the government's intention to control the population size directly via a pattern of medicalisation. These policies are particularly noteworthy in that the impetus for medicalisation came from the government. This can be interpreted as an application of Korean-style development or modernisation, which has historically been driven by government-initiated projects. Despite the similarity between the strategies of the two programs, their outcomes have differed significantly, as one seemed to succeed whereas the other has not. Therefore, comparisons of the two programs can increase our understanding of the concept and premises of medicalisation, especially when it is government-induced. These two programs were introduced about 50 years apart. Moreover, their authority was exerted to achieve opposite results: one was aimed at reducing the population, and the other was aimed at increasing it. These differences led to other differences that can explain their discrepant outcomes. Indeed, the programs differed with respect to the following: one was active when people considered themselves part of a nation in an act of mobilisation, whereas the other was active when people considered themselves individuals and rights-holders; one provided an incentive for people to act in accordance with a trend in the general population, and the other provided an incentive for people to act against a trend; one intervened with regard to the fertility of people, and the other intervened with regard to the infertility of people; one awakened a sense of parental responsibility for pre-existing children, and the other aroused parental responsibility for non-existent children. These differences have elicited different psychological responses and experiences of moral responsibility, yielding different outcomes. Examining the differences between the two cases may increase our understanding not only of the target subject matter but also of the hidden premises of medicalisation.

The medicalisation of everything

King, Nancy MP

nmpking@wakehealth.edu

It's easy to identify problems with medicalisation. Medicalisation can transform ordinary human emotions, like grief or fear, into pathologies; remove coping and support mechanisms from the control of families and communities and turn treatment authority over to medical experts; and focus attention on technology and data instead of on social context, nonmeasurables, and shared responsibility.

It's also easy to identify medicalisation's benefits. Identifying and naming as medical disorders conditions like PTSD, chronic fatigue syndrome (recently renamed SEID), and infertility can help ensure that they are taken seriously, and that treatments and other services are recognised as needed and paid for by health plans.

However, medicalisation may have deeper, broader, and more subtle effects. This presentation addresses some of those effects and asks how we should regard them.

- (1) Seeking patients' informed consent to health care is a fundamental practice. Yet there are no comparable informed consent requirements to most of the other interventions everyone encounters in life; informed consent remains limited to health care. The medicalisation of everything could change that; anything that has become medicalised acquires an informed consent requirement. This point is minor but noteworthy.
- (2) Medicalising preventive interventions could have some interesting consequences – namely, the medicalisation of ordinary healthy living. A healthy lifestyle could thus become labeled as preventive care. What could that mean for modern society?
- (3) Unchecked medicalisation can reduce medicine to mere technology. The most famous example is probably Carl Elliott's article in the magazine *Atlantic Monthly* on apotemnophilia – a body identity disorder in which patients seek amputations in order to feel whole. The treatment is straightforward for a surgeon. But is the surgeon's role morally appropriate? A less exotic example is assisted reproduction – a highly technical medical field associated with medicalising infertility, which has at least two significant consequences: (A) Genetic relationships with offspring, and the creation of new offspring, are prioritised over adoption of existing children, and assisted reproduction technologies, with their physical and fiscal costs, are normalised. (B) Individual transactions between would-be parents, specialty physicians, and health insurers take priority over social policy addressing the needs, interests, and values of communities and responsibility for global stewardship of resources; looking beyond personal choice is discouraged.
- (4) The medicalisation of death and dying also has significant implications. How do/should biotechnological attempts to prolong life and postpone death affect our views and expectations about life? How will/should the increased availability of medicalised physician-assisted death affect professional and public views about palliative care and aggressive treatment in life-limiting illness?

The relationship between health disparities and income inequality has obvious connections to the growth of medicalisation and the increasingly urgent need for health care cost containment. The allocation of social authority to biotechnological experts also revives a question that has always been critical for bioethics: Are health and health care like everything else, or different? Is bioethics right to focus on this specialised realm, or are bioethics scholars ducking the question of how our questions relate to the rest of life?

The normative logic of pharmaceutical insurance: A case study of the Canadian policy landscape

Komparic, Ana

ana.komparic@mail.utoronto.ca

Canada remains the only industrialized nation with a publicly-funded, universal health insurance scheme without accompanying national pharmaceutical insurance (pharmacare). Instead, Canada's pharmaceutical insurance landscape consists of a patchwork of public and private schemes and leaves a quarter of Canadians uninsured. Renewed calls for a national pharmacare scheme in Canada have resurfaced in the last several years amidst growing concerns of health inequalities and strained healthcare budgets. This paper characterizes the normative dimensions of the Canadian pharmacare policy discourse as identified through a case study analysis of policy documents and reports published between 2000 and 2014. Drawing on philosophical literature pertaining to the values of social justice and efficiency--particularly the works of Norman Daniels, Madison Powers and Ruth Faden, and Joseph Heath--the analysis renders explicit the ethical values, principles, and logics used to frame and justify the proposed policies. By analysing the Canadian pharmacare policy landscape, this paper articulates and critically evaluates how normative concepts of justice and efficiency are used in public and social policy debates to frame issues of inequality, access, scarcity, and risk. The analysis concludes with a reflection on how the values of efficiency and social justice are instructive to shaping pharmaceutical insurance policy and priority setting in light of the continued pharmaceuticalization of healthcare, where pharmaceuticals grow increasingly prominent in treatment plans and represent a growing percentage of healthcare spending.

Never mind that I am a complete orphan. The main thing is that I know the truth!

Konecna, Hana

hana@adamcr.cz

One of the paradigms of contemporary medicine is probably that Correct is what is Transparent, and that information is something we can pass unchanged to another person, with no effect on them and their surroundings. One of the manifestations of this philosophy is abolishing the anonymity in gamete donation in reproductive medicine, so called "open identity" system. That is justified by the rights enshrined in the Convention on the Rights of the Child (hereinafter "the Convention"). The child has to be explained from childhood that for his/her conception donated gametes were used, in adulthood s/he must be allowed to learn the identity of the donor and personally meet them. Given the increasing cross border reproductive care, there are also considerations to establish a mandatory global registry of donors.

The Convention declares the right of the child to know his/her parents (Art. 7 "Every child shall be registered immediately after birth and shall have the right from birth to a name, the right to a nationality and, as far as possible, the right to know their parents and right to their care"), the right to have contact with both parents, and obligation of States to "respect the right of the child to preserve his or her identity, including nationality, name and family relations as recognized by law without unlawful interference." in Art.8. All rights, as the situation in the international documents is, are formulated in very general terms, while remaining tasks of national legislation to establish them more scope.

The child's right to know their genetic origins are, however, explicitly formulated in the Model Family Code, which is the draft of the universal family model code for Europe. Art.

3.7 sets out the conditions under which the child may raise objections against parenthood, when it becomes clear that "legal parent" of the child is not the genetic parent.

Gamete donation is anonymous by law in the Czech Republic. In early 2013, some MPs attempted to amend the law and break the anonymity, but the amendment was not accepted. A new attempt appeared at the end of 2014, it is currently being discussed in Parliament. MPs justify the changes by the health risks and the child's right to know their origins. Proposers require, among other things, to write about using donated gametes to the Register of births. Our paper will discuss the strategy of "open identity" from the perspective of information theory, theories of identity and attachment theory.

Aging, dis-function and access to care

Lanoix, Monique

mlanoix@ustpaul.ca

Aging provides a critical lens into the complexities of disease management, as well as the theoretical and policy responses to the inevitable phenomenon most individuals will face. In this paper, my focus is on the implications of Norman Daniels's prudential lifespan account as it pertains to aging individuals' access to health services and to the consequent medicalization of aging.

Daniels has written extensively on the topic of health care in the case of aging individuals (1985; 1988; 2008; 2013) and he anchors his account on several key notions, one of which is species typical functioning. In order to argue that older citizens have a right to access some health care services, and to stay true to the spirit of the Rawlsian framework in which he operates, Daniels has to make the case that opportunity remains central even for individuals who are in the latter part of their lives. If Rawls ties equality of opportunity to jobs and careers, opportunity must take on a larger meaning in the prudential lifespan account if the concept of fair opportunity is "to play an important role over the lifespan and not just in certain stages of life" (1988, 74). Using Christopher Boorse's biostatistical theory of health, Daniels adopts the notion of species typical functioning as "the typical *modus operandi* of the internal physiological machinery of a species" (1977, 550). This is particularly useful for Daniels as it helps adjust expectations for opportunities as individuals grow older while grounding these expectations on a seemingly empirical and assessable measure.

Much has been written on the contested notion of species typical functioning. Criticisms have been put forward by disability theorists who question its social implications (Amundson 2000; Silvers 1998) and by others who target its usefulness for Daniels's account (Krag 2012). Recently, a larger discussion has emerged as to the accuracy and effectiveness of defining health using Boorse's theory (*Journal of Medicine and Philosophy*, 2014). Significantly, aging calls into question a uniform ideal of functioning since aging is typically a period when many diseases arise. However, whether or not aging should be considered a deviation from species typical functioning is left unresolved by Boorse (2014).

I do not intend to question the usefulness of such a concept in the assessment of health or disease. Nor am I concerned with labelling aging either as a disease or a fact of life. Rather, my analysis is centred on the manner in which species typical functioning and opportunity become welded in Daniels's account. I side with disability theorists and I argue against the use of this concept in a theory of health care resource allocation. I make the case that species typical functioning only serves to medicalize aging with unwanted consequences. First, it fosters a reductionist approach to the complex medical and social phenomenon that is aging. Second, it cannot account for the complexities of chronic care provision, which is the model of care provision that best suits the needs of most aging individuals.

Whose the baby, and whose the birth? On the unconstitutional regulation of unassisted birth in Israel

Leissner, Naomi

jomi6666@gmail.com

Childbirth is a good measure of the process of medicalization. It's old news by now, how the members of the medical profession wrested normal childbirth from the hands of its traditional owners, the midwives, and, to all intents and purposes, from the hands of the birthing women themselves.

In the industrialized world, the bulk of the process spread over the 18th Century. It began (roughly) with the entry of the doctors into the homes of wealthy women giving birth. It ended (roughly) with the universal hospitalization of childbirth, a goal that was attained in most industrialized countries over the course of the 20th Century.

Despite the same general similarities in the history of birth, the details of the process of the hospitalization of birth varied from place to place. In some it occurred earlier than in others; the means whereby women were brought into the hospitals varied, as did the degree of medical intervention in birth once inside.

The reactions of women to the medicalization of birth varied accordingly, both in terms of timing and of extent. In Britain, for example, as early as the 1960s, women established an organization named the Society for the Prevention on Cruelty to Pregnant Women. In other places it took longer for women to organize themselves. Most commonly, small groups of women began giving birth at home, assisted by trained homebirth midwives. The most radical among them would choose lay-midwives, rather than medically trained nurse-midwives.

From about the 1980s onward, some countries began introducing reforms into their birth systems, inter alia, with the aim of humanizing birth. But not all of them did, and not all of them went "far enough." One result has been the inception of a small but growing group of "stalwarts," who choose to give birth not just out of hospital, and not just *sans* medically trained assistants but with no assistance at all. It is thought that the movement for "unassisted birth" is strongest in those countries where childbirth reforms have been slowest in coming, and that description would certainly fit Israel.

The current presentation seeks to explore aspects of the "unassisted childbirth" movement as it has emerged in Israel, a country with an extremely high medicalization record, with childbirth being no exception to the rule. Unsurprisingly, the authorities have clamped down hard against such "heresy", but it has not done so directly, for example, through laws that regulate childbirth, but rather indirectly -- through laws that regulate the registration of babies.

Specifically, this presentation concerns the 2005 amendment to Israel's Population Registry Law (1965). The reason for the relevant enactment was a bizarre, if horrific, story concerning a father and mother and the rape of a fifteen year-old baby-sitter in an ultra-orthodox neighborhood in Jerusalem. The result was a law that deeply infringes upon birthing women's basic rights, including their rights to privacy, bodily autonomy and refusal of medical treatment.

Resisting medicalization and geneticization? Young people's views

Levitt, Mairi

m.levitt@lancaster.ac.uk

Medicalization and geneticization, are not simply processes to be measured empirically and proved or disproved (ten Have, 2001; Arnason, 2007). However, people's own

understandings are not irrelevant since the processes involved in geneticization, described originally by Abby Lippman, are said to clearly impact on people's lives; how we think of ourselves and others, our relationships, commitments and values (Lippman, 1991, 1992).

This paper discusses material gathered from young people responding to current genetic research and applications which could be seen as examples of medicalization and, in most cases, geneticization i.e. aspects of life previously outside the realm of medicine become open to intervention, such as normal height variations in children, ageing and morality, and differences between individuals are explained by genetics. How these particular examples were to be seen, e.g. positively, negatively or in some other way, was an open question. In order to 'dig deeper' into their views the young people then completed a questionnaire designed to collect more general attitudes to science and technology and their ideas of nature and the natural. Finally, they were invited to give their own suggestions for 'improving humans' and asked if it would be a good idea to carry out these improvements.

The responses of the younger classes, in which most pupils were 12 years old and all were in the middle band of ability, are the main focus of this paper. They participated in the research in their multifaith religious education classes, though not with their usual teacher. In these classes they had not covered any of the topics before, but were accustomed to discuss their views and were expected to respect the views of others.

The children's justifications for their views were diverse but themes²⁵ running through their responses included:

1. A resistance to the pathologising of normal variations among human beings e.g. in height.
2. Enthusiasm for technologies with clear health benefits but opposition to technologies that go further because of likely or possible consequences.
3. Criticism of the idea that there are clear categories of traits and that these can be looked at in isolation rather than considering the person as a whole.
4. Individual benefit and choice were often seen as important but did not necessarily prevail against wider social and political considerations.

The young people might be described as resisting medicalization and geneticization to varying degrees. The significance, if any, of such attitudes, in adults or children, will be discussed.

Holistic medicalization: The concepts of health and disease in systems (P4) medicine

Vogt, Henrik; Getz, Linn

vogt.henrik@gmail.com

Background and aim: Systems (P4) medicine is a medical application of systems biology, a technologically driven, post-genomic merger of molecular biology and systems theory. It is currently promoted as biomedicine's newest vision of a *personalized* or *precision* medicine to be centered in primary care. Intriguingly, it has been claimed to involve a revolutionary understanding of health and disease that is at once presented as *holistic* and at the same time as enabling a *quantification of wellness* (health) and a *demystification of disease*. We aim to answer the following questions: 1) How does the conceptual understanding of health and health problems found in P4 medicine relate to traditional conceptions in the philosophy of medicine? In particular: In what ways, if any, can it be considered as *holistic* and as involving a revolution? 2) What may the implications of this understanding be with regard to the problem of medicalization, defined as the process by which aspects of human life come to be considered medical issues and underlain medical control?

²⁵ These themes are tentative as the data is not yet fully analysed.

Methods and material: We performed a conceptual analysis of a material consisting of authoritative publications outlining systems (P4) medicine from 2004 to the present in light of strategically chosen literature in the philosophies of health and disease and systems biology.

Results and conclusions: Systems (P4) medicine conceptualizes health and disease as complex network states, drawing on network theory from engineering and physics. We call the resulting view *mechanistic holism*. It explicitly takes biomedicine from associating diseases with single components (e.g. genes) and simple, linear mechanisms towards a systems view of health and disease as resulting from highly complex, non-linear processes. This corresponds to move towards a so-called *physiological conception* of health. At the same time, it retains a naturalistic view of health and health problems as mechanistic, deterministic, predictable and quantifiable phenomena that is also reductionist in insisting that the whole should be understood *in terms of molecules* and their interactions. In this way it combines a holistic physiological conceptual element, with a so-called *ontological conception* that reduces disease and health as network states to something very concrete, thing-like and controllable. We argue that this combination of viewing health and disease as a) something complex and non-linear that pertains to wholes over time, but b) still renders these phenomena as something quantifiable and controllable points towards attempts at what we can call *holistic control*. This will involve technologically enabled “holistic” measurements of “big data” pertaining to each individual, “holistic” modelling of health as multi-level, non-linear phenomena and ditto “holistic”, non-linear engineering of all factors throughout life, notably at the molecular level. We argue that – whatever the gains – this will, in various ways, translate into higher degrees of medicalization.

Medicalization of the mind and human love...Intimacy and sexuality in the context of dementia

Mahieu, Lieslot

Lieslot.Mahieu@med.kuleuven.be

Global population aging confronts us with a large variety of challenges. Among other things, population aging seems to be driving the emergence of the dementia epidemic. Research predicts that the number of people with dementia will double every 20 years. Contemporary bioethics does pay considerable attention to the ethical aspects of dementia care. Although sexuality has been defined by the World Health Organization (WHO) as a ‘central aspect of being human throughout life’,²⁶ ethical issues of sexuality especially as experienced by institutionalized persons with dementia often get overlooked. Yet, expressions of sexuality by older people with dementia often cause ethical dilemmas.

The existing ethics literature on this topic generally applies an implicit philosophical anthropology that favors the principle of respect for autonomy and the concomitant notion of informed consent. In other words, capacity to consent appears to be a predominating factor in assessing the moral permissibility of sexual engagement by people with dementia. At first sight, this seems pretty self-evident. The most common definitions of sexual assault indeed do focus on the non-consensuality of the sexual act in question.

The current focus on cognitive capacity, however, can also be said to remove the choice to partake in sexual intimacy from people with dementia by medicalizing it into a framework of supervised informed consent. By doing so, it plays into the denial of this population’s sexual

²⁶ WHO (2006) *Defining sexual health: Report of a technical consultation on sexual health, 28-31 January 2002.*, World Health Organization: Geneva.

rights. Not only does it tend to disregard the sexual longings of people with dementia as their ability to make day-to-day decisions might easily be underestimated; it also fails to give an accurate picture of what human sexuality entails, regardless of whether one is competent or not. After all, sexual engagement is based on more than rational decision-making alone.

Our thesis is that a more inclusive philosophical anthropology is needed that also heeds the fate of this growing population. Drawing on the tradition of phenomenology, we will chalk out an anthropological framework that rests on four fundamental characteristics of human existence: the decentered self, human embodiment, being-in-the-world and being-with-others.

Enrolling the global poor in clinical research - What is the essential ethical concern?

Malmqvist, Erik

erik.malmqvist@liu.se

Clinical trials of new medical interventions are increasingly located in low- and middle-income countries (LMICs). Though advantageous to pharmaceutical companies and other research sponsors, such “offshoring” of trials is ethically controversial. Recently, scholars and advocacy groups have shown that those who participate in international research are often among the poorest and most vulnerable. Many participants in LMICs are impoverished people who seek to supplement their income or sick patients who have no other way of accessing a doctor or receiving drugs they need.

Enrolling these groups in research is described as ethically problematic. But this concern is rarely well articulated. Why is it a problem that the global poor participate in research in exchange for money or needed healthcare? What is the essential ethical concern with enrolling these particular groups? This is the question I propose to discuss.

Surely, clinical trials in LMICs raise several legitimate worries. In many documented cases it seems clear that participants have been exposed to unjustified risks or harms or enrolled without giving valid consent. However, while such concerns are magnified when researchers enrol poor people without access to healthcare, they are not unique to trials of this type. Problems concerning risks vs benefits and informed consent are endemic to clinical research. Moreover, they generally have practical solutions. They can be effectively curbed by appropriate ethical review and oversight mechanisms, which are currently being strengthened in many LMICs.

I suggest that there is another, less familiar but arguably more fundamental, ethical concern with enrolling the global poor in clinical trials. Severe poverty and lack of access to health care in LMICs are deeply morally unacceptable. Overcoming these conditions should be on top of our agenda. However, when we as potential patients rely on them for the drugs we need we instead gain a powerful interest in their preservation. So do pharmaceutical firms who depend on these conditions to secure their profits. We (and they) become even more deeply invested in a situation that ought not to be. I end by discussing how research in LMICs can be conducted without creating disincentives to reduce poverty and improve access to healthcare in these countries.

The ethics of terminal sedation

Materstvedt, Lars Johan

lars.johan.materstvedt@ntnu.no

Terminal sedation (TS) may be described as the most radical or extreme version of palliative sedation (PS). In its new, 2014 guidelines on PS, the Norwegian Medical Association (NMA)

provides the following definition: «By palliative sedation is meant pharmacological depression of the level of consciousness in order to alleviate suffering that cannot be relieved in any other way.» TS involves the deepest form of such pharmacological depression, and the patient is normally kept in a state of total unconsciousness until death occurs - hence I have in an article in *Lancet Oncology* in 2009, with Swiss physician and bioethicist Georg Bosshard as co-author, called TS «deep and continuous palliative sedation» (DCPS). In this lecture, I address three issues that make DCPS particularly challenging ethically and clinically: First, that it entails the destruction of patient autonomy; second, that the treatment strategy might have a life-shortening effect; and third, that the indication for DCPS is a controversial matter indeed. As regards the second issue, many guidelines on PS state that it should only be given to patients with a life expectancy of a few days or up to 1-2 weeks at most. However, the NMA states that PS «shall normally» be given only that close to death, and accordingly the treatment may be extended beyond the final phase - with an increased risk that the patient may die from complications or adverse effects associated with the treatment. When it comes to the grounds for initiating PS, the NMA holds that «mental symptoms alone are only in rare cases an indication for palliative sedation.» I discuss whether or not existential suffering may be considered as a mental «symptom».

Medicalisation and enhancement in public health

McKeown, Alex

Alex.McKeown@bristol.ac.uk

The need to move as much healthcare provision as possible ‘upstream’ to extend healthy longevity is becoming increasingly important. Public health medicine and policy must find ways to achieve this as our ability to prevent illness and disease grows. Depending on what kinds of interventions are required, it may entail the ‘medicalisation’ of health states previously deemed beyond the nominally, and traditionally, remedial boundaries of medicine and healthcare. Furthermore, a side-effect of successfully extending healthy longevity across an entire population through illness prevention will be that public health is enhanced. Consequently, on this view, enhancement of some kind is a necessary feature of effective public health medicine and policy. If this is true, the question of increasing medicalisation must be taken seriously, since if the trend away from remediation to prevention continues, medical professionals may need to rethink the boundaries of their work. Adequate healthcare provision must respond to the needs of society, and changes to the latter will influence the former. If public health provision becomes increasingly preventative, the patient-physician relationship will change correspondingly.

Numerous concerns about both medicalisation and enhancement have been raised. For example, it has been argued that medicalising normal health may unnecessarily stigmatise people receiving unnecessary care while, in some cases, generating profit for those producing the medical ‘solutions’. Similarly, a frequent criticism of enhancements is that it is likely that their availability would be unequal since they would not take priority for subsidisation in the same way as treatments for serious diseases, for example. Hence it is argued that those who could afford to buy enhancements would further entrench the socio-economic advantages over others that they already enjoy. These are reasonable concerns in particular instances. However, it is not clear whether either medicalisation or enhancement is *intrinsically* ethically troubling, and thus whether or not concerns are justified in general. For example, the ‘medicalisation’ of public health could be as benign as health promotion, or the clinical prescription of exercise; and by analogy to interventions such as vaccination or water fluoridation, something which could cheaply and safely be administered to an entire

population, and enhance by preventing illness, could be incorporated into public health provision without exacerbating existing socio-economic disparities.

Nevertheless, if enhancement has an implicit role to play in public health, regulatory and policy arrangements should reflect this, particularly in instances in which the associated medicalisation of normal health *may* threaten to exploit the recipients of healthcare. Conceptions of the responsibilities of the medical professions will need to change if it is no longer assumed that restoration of normality constitutes the boundary of appropriate practice. An acceptance will be needed that the normative goals of medicine may include procedures which inevitably enhance rather than treat. Recognition that a growing commitment to optimising healthy longevity may entail the provision of interventions which enhance - and thus medicalise - into standard population medical care has significant consequences for public health policy, which this paper will investigate.

Diderot and human biology: Between magical healing and pernicious medicalization

McLennan, Matthew R

mmclennan@ustpaul.ca

The rise of medicalization is a practical problem admitting of a multitude of methodological approaches. One of these approaches is to read medicalization through the lens of the history of ideas. By no means eschewing a broader analysis, doing so sheds additional light on the problem while revealing the profoundly ambivalent if not ironical way that the medicalization of human life has unfolded. It also provides historical grist for speculation on how current problems might be handled by revisiting promising questionings and engagements.

In my paper I start from the widely-known fact that in cleaving soul from body, René Descartes philosophically founded modern subjectivity and its unique intractability. But he also thereby founded the mechanistic materialist interpretation of human anatomy. This was subsequently adopted by La Mettrie and the Encyclopaedists before influencing Bichat at the anatomo-clinical model of the 19th Century. The irony is that the philosopher's gesture articulates the human subject while at the same time endangering it, precisely by giving free rein to the mechanistic and technoscientific approach to medicine that will come to be vigorously critiqued in the 20th and 21st Centuries. Perhaps more troubling still, some critiques of post-Cartesian medicalization encourage a certain magical or post-rational approach to human suffering by exorcising the machine from the ghost. In fact, a good many of such critiques defend magical thinking and skepticism towards scientific rationality quite openly. The impression of a (false) dichotomy between medicalization and an abandonment of scientific materialism is thereby created and encouraged.

With this in mind, my paper approaches Denis Diderot as a case study in how French materialism in the wake of Descartes handled the question of human biology and its specifically medical and hygienic applications. Diderot is a crucial figure because he struggles to articulate a humane as opposed to narrowly technoscientific approach to medicine, sexuality and health from within a rigorously materialistic framework. As such, he offers a fascinating case study in thinking beyond the false dichotomy of narrow technoscientific medicine on one side, and a return to magical or post-rational healing practices on the other. My reconstruction of Diderot's philosophy of human biology and its practical applications is thus offered in the spirit of highlighting an important precedent in the history of ideas, wherein materialism was thought against the grain of the medicalization that would follow.

Medicalisation as dealing with uncertainty?

Melse, Johan

johan.melse@rivm.nl

“His mother sighs with relief, pff, I’ve known it for a long time, I’m glad that he now really has ADHD.” This kind of reactions to doctors giving medical labels is quite well known - and quite understandable. After all, we have organised our society around such labels: with it you’ll get professional and financial help, without it you will not - even if it is obvious to you and maybe even professionals that you and your son need it.

What lies behind this kind of medicalisation with its binary thinking and ‘riskification’. My line of inquiry is what this says about the way we deal with uncertainty. Why is uncertainty generally deemed a bad thing? And is that necessarily so? Or may there be other ways of looking at uncertainty that might open up new possibilities instead of closing into either/or? With the help of Ravetz and Lyotard among others, I aim to sketch another way of dealing with uncertainty, as citizens, scientists, professionals.

Uterus transplantation: The only option thus the good one?

Mertes, Heidi

Heidi.Mertes@ugent.be

Introduction: The most recent example of the ongoing medicalization of reproduction is the first healthy live birth from a transplanted uterus. That this is an impressive achievement that is greatly appreciated by the parents is beyond contestation. Also for the physicians, the rationale seems straightforward: there are no other valid options available to the patient and therefore risks, limited utility or excessive costs are overruled by the duty to help patients in need.

Central research questions: Is uterus transplantation really the best option available for the concerning patients as a group or is this innovation driven by the technological imperative rather than the best interest of all parties concerned?

Results: Even for women lacking a functional uterus, uterus transplantation is *not* their only option for having a family life, becoming a parent or even a genetic parent. It *is* their only option of carrying a baby to term. The validity of the claim is thus largely dependent on the specific needs or desires of the patient.

Also, the only-option-argument does not overrule a thorough risk-benefit and utility analysis. Risks arise for all parties involved: for live donors (although research is underway to use uteri from deceased donors), for the receivers and for the resulting children. There are risks of infection, blood clots, and premature birth due to graft rejection and unknown risks linked to the Rokitansky-syndrome (which is one of the prime indications for uterus transplants). Little is known about if and how the syndrome may be inherited.

One might argue that the adults involved can give their informed consent and that risks for the resulting children can be defended based on the non-identity problem. Yet, when several options are available (as in this case uterus transplantation versus adoption, surrogacy or childlessness), there are good reasons to select the option that is likely to have the best outcome, which in this case is not necessarily uterus transplantation.

Looking at the utility, while the procedure may have been worthwhile for the woman who delivered the healthy baby, other couples will be faced with false hope, disappointment and despair. In reproductive medicine it is important to remember that what makes people unhappy is not their affliction – infertility or childlessness – *per se*, but rather the (false) belief that children are a necessary requirement for a happy and fulfilling life. Accepting

risks, excessive costs and low utility to satisfy the desire for bearing children reinforces this false belief, whereas its modification by counselling and support in the grieving process may lead to equally satisfying outcomes.

Conclusions: Despite the proof-of-principle that it is a successful medical treatment for a clear pathology, there are good reasons to be critical about uterus transplantation if we consider the ‘no treatment’ option to also be a valid option.

Obstetric ultrasound and the social structures of sympathy

Mills, Catherine

catherine.mills@monash.edu

A central driver of the process of the medicalization of pregnancy and childbirth since the 1950s was the invention and development of obstetric ultrasound: as Nicholson and Fleming (2013, 3) write, “[t]he ultrasound scanner was both a major agent for and a potent symbol of the medicalization of childbirth”. In addition, though, obstetric ultrasound has been a central agent in the normalization of the fetus. Ultrasound technology has not only been crucial to the generation of normal range measurements for an ever-more extensive list of foetal parameters; it has also allowed for and perhaps incited an ever-stronger desire for a ‘normal, healthy baby’, sometimes of a particular sex. As a consequence, ultrasound contributes in fundamental ways to decisions about terminations of pregnancy on the basis of foetal characteristics such as malformations or genitalia. The claim of this paper is that ultrasound not only makes such decisions possible – by revealing foetal characteristics that would otherwise not be detected prenatally – but transforms the moral status of the foetus in ways that are yet to be fully appreciated.

While feminist scholars have long argued that ultrasound impacts on the politics of abortion and the cultural status of the foetus, the specifically ethical implications of ultrasound have been less clear. The capacity of ultrasound to shape the ethics of abortion has been considered in several interventions in moral philosophy and bioethics. For instance, Michael Slote suggests that images of the foetus may affect the empathic relation that can be maintained with them, while Paul Lauritzen argues that such images have persuasive force: they are “visual arguments”. In this paper, I deepen the analysis of this capacity of obstetric ultrasound to shape ethical approaches to the foetus and termination of pregnancy, especially in the context of medical normalization.

I argue that ultrasound technology mediates the ethics of abortion in several ways. First, ultrasound helps to establish social relationships to the foetus, and these entail morally significant emotions such as sympathy. Second, though, in the context of medical normalization, sympathy is often structured in accordance with regimes of social and medical norms that (more or less strongly) prescribe acceptable modes of bodily appearance. The social structuration of sympathy highlights how ethical responses are susceptible to the ways in which images are framed, both visually and narratively. As a consequence of this, ultrasound has the capacity to make the moral status of the foetus contingent upon social circumstances, thus allowing for a differential inclusion of the foetus in moral community.

Complexity of a bioethical analysis of medicalization

Murano, Maria Cristina

maria.cristina.murano@liu.se

The concept of medicalization has been introduced in the literature in the '70s, by authors like Zola, Illich and Foucault. They expressed their concern about the increasing relevance that medicine bore within society. Although for different reasons, they described it as an institution which exercises social control. Their theories had considerable influence and they increasingly attracted the interest of many scholars from diverse backgrounds and perspectives. Sociologists like Conrad and Halfmann, for instance, have provided descriptions of medicalization as a social process, which should be seen as a value-neutral multifaceted phenomenon that always occurs in rotation with its reverse: demedicalization. Whereas philosophical discussions on the ends and goals of medicine, proposed for example by Pellegrino, have further problematized the debate and clearly expressed the need to reflect on the nature of medicine itself. On this ground, it was possible to suggest some guidelines and limitations on its use and means.

Considering the strong mixed reactions brought by this concept, the lack identified in the literature of a comprehensive bioethical analysis of medicalization is surprising. In this presentation, I will suggest some of the difficulties at stake with it: the complexity of the phenomenon, conceptual limitations and the contextual component.

The bioethical examination of a sociocultural process seems to be particularly difficult itself, because it has to take into account a complex interaction of individual and social dynamics. However, in the case of medicalization some peculiar issues arise already from the definition as 'process by which non medical problems are defined and treated as medical problems'. This designation seems to assume that everyone agrees on what is a medical condition and on the existence of a sharp distinction between medical and non medical ones. Yet, the debate around theories of health is considerable: beside the broad range of descriptions between the two antipodes of the descriptive-biological and the normative-holistic ones, more recent studies propose dynamic characterizations. If health is not only a given condition, but also a state that we contribute to create, it is questionable whether a clear-cut distinction between social and biological problems should be drawn. For those reasons, it seems also necessary to perform a case by case bioethical investigation.

Despite these difficulties, dilemmas about the use of medicine to modify human bodies remain fundamental. If the increase of technological opportunities has changed our worldview and aspirations, aims and needs, it seems that medicine assumes a crucial role in shaping our identities. We tend to medicalize ourselves not only when there is an actual disease, but also when there is a risk of a disabling condition. We are fascinated by the possibility to provide us and our beloved with better chances in life. If we consider medicalization as a dynamic social process, that we have been contributing to create through the years, we can perceive ourselves as active moral agents, who can play an important role in determining whether a specific case of medicalization is bad or good.

PGD and the duty to provide an open future

Myskja, Bjorn

bjorn.myskja@ntnu.no

Dan Brock suggests that the right to reproductive freedom and parent's judgmental room in upbringing may include the right to use positive selection in order to enhance the future child's opportunities in life. This can theoretically be done through preimplantation genetic

diagnosis (PGD). Dena Davies holds that creating a child who will be irreversibly determined by the parents' idea of the good life is contrary to the principle of treating each person as an end in herself. She claims that this violates the child's right to an open future, invoking Feinberg's argument that a child's capacity for future autonomous choice should not be unduly limited by the parents' choices in raising their child. Dena Davies' Kantian version of the open future-argument seems to stumble on the Non-Identity Problem, as described by Parfit and others, which implies that a procreative choice cannot affect the rights of *this* person, as long as her life is better than not being born. Any other choice means that some other person would be brought into life.

This presentation argues that a more promising Kantian approach would be to focus on parental *duties*, rather than future children's rights. Parents bring children into the world without asking them, thus establishing a relationship with a non-consenting partner. Kant holds that this gives the parents a duty to care for their children. The duty implies a parental right to "manage and develop"; that is to make decisions regarding the child's life, until "his emancipation". Arguably, this right may include using PGD for selection. However, this right is derived from the duty to enable the children to become autonomous beings establishing their own purposes in life. Will exercising this right through positive selection of beneficial traits be a way to fulfill this duty?

Preventing the creation of a life that we know will be short and painful with no possibility of autonomy through negative selection is acceptable or even mandatory, as the birth will not result in an autonomous life. However, in the absence of knowledge about future circumstances, we neither have a duty nor a right to determine positive characteristics of the future child, as that would mean making the child a means for the parents' purposes. We merely have a duty to provide an open future when we take a reproductive choice to bring children into the world. We should not decide on specific characteristics of that future being – even when such decisions are possible.

Biobanks and returning individual research results: Latvian policy in the light of current discussions

Neiders, Ivars

ivars.neiders@rsu.lv

The issue of returning individual research results to participants in genomic research studies has been a hot topic in research ethics already for many years. However, in spite of the considerable amount of ink spilled there is still no consensus about what would be the best policy. How incidental findings should be managed by researchers? Is there a duty to inform participants about incidental findings? Is there a principal difference between incidental findings in genomic research and in clinical research? What constitutes incidental findings in genomic research? If researchers should inform participants about incidental findings, what would be the proper way to do it? These and similar questions are at the center of current discussions about managing incidental findings in population based biobank research. Different biobanks in different countries deal with these issues in different ways. In this paper I will analyze the current policies of Genome Database of Latvian Population (GDLP). This is a state funded biobank processed and coordinated by Latvian Biomedical Research and Study Centre, established in 2006. In particular, I will consider how the Latvian policies look in the light of the current discussions about managing incidental findings. Also I will come up with some suggestions of improvement of the policies.

The “innocence” of phenomenological ethics.

Nortvedt, Per

per.nortvedt@medisin.uio.no

Since Husserl, meta ethical questions have been central to the phenomenological tradition. Among the most prominent philosophers of phenomenological ethics in the post-Husserlian period have been Hans Jonas, K.E Loegstrup and Emmanuel Levinas (noting that Levinasian ethics early took a metaphysical turn based upon a critique of Husserlian epistemology and ontology). The basic meta ethical assumptions in the ethical theories of the phenomenological tradition have been that moral sensibilities and how to become morally responsible is intrinsically related to what it is to be a human being as interdependent and relational creatures. The phenomenological tradition in ethics argues that moral demands are *epiphanies*, they are nonoptional and nondeliberate experiential manifestations of moral realities. Moreover, phenomenological ethics argues that ethical sensitivity is primordial, and that the constitution of moral sensitivity is original, ontological and essential to moral consciousness.

This paper will illuminate two important shortages of a standard phenomenological position in ethics: First, it is normatively underdetermined. It is too thin to give proper moral advices in cases of moral conflict. It cannot adjudicate between morally right or morally wrong acts, but only explain what is the origin of moral reasons and sensibilities. Further, and most important, the phenomenological position in ethics paints a too simplistic and naïve picture of the human condition and our moral psychology. There are mounting evidence that both moral sentiments as well as moral reasons are motivationally unreliable confronted with political, ideological and various forms of immoral influences. A vast empirical and philosophical literature on collective evil-doing in the 20th century indicates that basic moral intuitions and sentiments are of little help in preventing ordinary individuals and professions from being involved in large scale violence. The question is to what extent this is detrimental to the phenomenological position in moral philosophy as such.

Do Ambient Assisted Living technologies medicalise care for people with dementia?

Novitzky, Peter

pnovitzky@gmail.com

One of the novel approaches to tackle the increasing burden of ageing societies, and the care of the growing number of people affected with dementia worldwide, is the introduction of Ambient Assisted Living (AAL) technologies into private homes and nursing homes. The leading motivation in developing AAL technologies is to empower people with dementia. Other views see in AAL a threat of medicalisation of homes and dementia care. This presentation will provide an overview of the ethical aspects of this debate.

The anthropological approach of care optimize Quaternary Prevention (P4)

Ouvrard, Patrick

patrick.ouvrard@unimedia.fr

The anthropological approach of care optimizes P4 taking account of the patient's socio-cultural context and of his (patient) representations of diseases, of medicines and of therapists. It is a prerequisite for a coherent and adapted family medicine practice. Our

attention should be given to the patient, not the disease. The disequilibrium due to the disease affects the patient as a whole. (first do not harm)

The patient who consults a GP is haunted by fears of the most often imaginary and sometimes true disease. The physician's role is to reassure him, to show him the unfounded of his anxieties.

The fears are fully depending of the patient culture. There are so many diseases that patients. Go further reflection and contextual analysis of the other and of itself can help to improve the triangular relationship patient / disease / doctor and increase efficiency.

Medicalisation: Is health care possible without it?

Papagounos, Georgios

papagounos@gmail.com

Medicalisation is not a new phenomenon in health care. In this paper I will argue that it is the outcome of a long process involving human needs and the changing human desires on the one hand, and the increasing knowledge of human biology and chemistry along with technological developments which aimed at improving medical practice and allowing it to set new goals and broaden the legitimate domains of intervention, on the other. Parallel to these developments was the more rigorous training of those who would legitimately chart the domain of health and decide which individuals and the means they could employ to make it accessible to the public.

The process of the medicalisation of health care was, to a great extent, the outcome of the elevation of the word health from describing a physical or mental condition of a human being to a word denoting a value. It should be kept in mind that in classical Political Economy the value of something was that which somebody would be willing to pay to acquire the object in question or attain a certain state physical or mental. This event resulted in the need, first, to specify who could legitimately create that which had the specific value and, second, who could legitimately determine the need to attain the desired state. Health became a condition which could be maintained or recovered when lost. Very early on, in the course of this transition, specific groups demanded and gained the right and the trust of the public to be the ones entitled to manage health and dispense it when necessary. The essential component which these particular groups claim for themselves ranged from the ability to evoke either supernatural entities that would restore health or specific skills which were acquired through the study of the human body and its functions along with the experience to apply this knowledge. The existence of such groups and the power and authority which they had was present as early as in the second millennium in Egypt as it is evident in documents such as the Edwin Smith Surgical Papyrus and the Ebers Papyrus.

The desire and not the need of human beings to increase both qualitatively and quantitatively their health resulted, naturally, in the corresponding increase of the value itself, i.e., the cost of the specific good, namely, health. It also resulted in the consolidation of the group of people who would be the only ones allowed to be involved in health matters and provide appropriate services. This development led to the rigorous description of the domain of non-health which was under the jurisdiction of physicians. These developments were followed by complimentary processes which led to the full medicalisation of human life.

Medicalization of obesity is a good thing

Paranhos, Flavio RL

flavioparanhos@uol.com.br

Obesity has become a major concern of many developed and developing countries, to the point that it is viewed as an “epidemic”. The mere use of the term “epidemic” already reveals the nature of the issue: we are talking about a disease. But, are we? According to the American Medical Association, yes. However, this is not an uncontroversial issue. The consequences of medicalizing obesity are not only social, but economic. If obesity is a disease, it should be covered by health insurances. And this consequence leads to another: if obesity is an epidemic disease, and its treatment is to be paid by health insurances, the cost may rise significantly for all – obese and non-obese. That’s when people start to ask: Is this fair? Should we pay more because these ‘fatties’ do not have enough will power? The debate over free will is as ancient as philosophy itself. One of the most reasonable approaches being that of Daniel Dennet (Freedom Evolves, 2003), the ‘compatibilist’ approach. However, there is one key concept in Dennet’s theory which does not fit well in the puzzle of free will as a social construct. According to him, human beings want to believe they have free will because “they want to be held accountable” (p. 292). Actually, it is the other way around. People want to believe there is free will so judgments of others’ responsibilities will be legitimate. Going back to the obesity case, there is plenty of evidence (e.g., Puhl et al, 2012, Sikorski et al, 2012) showing how obese people are bullied on the basis of their assumed lack of will, which becomes lack of character, therefore morally blameful. Moral discourse in the political arena becomes ideology. The majority of articles published in the nonscientific press strongly opposes the medicalization of obesity. One emblematic example would be the article by Michael Tanner in the right-wing publication National Review (2013): “(...) the AMA decision shifts responsibility for weight loss from the individual to society at large, while expanded Medicare and insurance coverage socialize the cost of treating obesity, thereby inviting all manner of government mischief. After all, if being fat is not our fault, the blame must lie with food companies, advertising, or other things that need to be regulated. And if you and I have to pay for the food and exercise choices of others, we should have a say in those choices.” Surprisingly, a recent editorial at one of the most respected scientific journals (Katz DL. Obesity is not a disease, Nature, 2014) echoed such an opinion, with change of perspective, shifting from the political to the scientific. However, this editorial took into account only pharmacological and surgical interventions as a compulsory result of medicalizing obesity. This is a mistake. Medicalization of obesity does not necessarily mean “pharmacolization” or “surgicalization”. It may also mean customized diets and physical activities. And above all, it means freedom from the burden of a negative stereotype. Medicalization of obesity is, therefore, a good thing.

Elderly and palliative care

Pegoraro, Renzo

renzo.pegoraro@fondazionelanza.it

The development of palliative care has been primarily directed toward cancer patients and certain chronic degenerative diseases at an early onset. However, the current social context reveals a growing need for assistance and palliative care for the elderly at the end of life. This is due in part to the increasing population of elderly and also to the complex process of aging, which exhibits particular features both by reason of a higher frequency of co-morbidity, as

well as, an objective lack of autonomy in the elderly (for the progressive loss of physical and cognitive functions, dementia ...).

The approach to palliative care for the elderly and for the “older elderly” calls for a special competency and a specific organization which would take into account their particular conditions and needs. Still, assistance in this area has undergone a general tendency toward “medicalization” and continues to be based on a pharmacological and technological approach, rather than a holistic approach which would include a global vision of the needs of the person.

Rediscovering the “care of global pain” perspective, which was typical of the original inspirations leading toward palliative care, is offered as the most adequate way to undergo palliative care in a personalized way which best responds to the clinical, psychological, spiritual and social needs of the elderly. The path of “de-medicalization” in the care of the elderly especially occurs through the “relational network” which emerges as a genuine response to the “loss of meaning” that characterizes the elderly condition, often alone, abandoned or “marginalized” by the active portion of society. It is important to have a context in which to recognize and re-assign value to the person who all too often has to confront solitude, depression and the psycho-physical consequences of the terminal stage of life, which often is only resolved at the medical-pharmacological level.

The holistic approach, inspired by the full development of the dignity of the human person, constitutes, therefore, a valid response regarding the program of assistance, offering good care focused on relational aspects, in order to avoid solitude, the risk of depression and to satisfy the concrete physical and spiritual needs of the terminal elderly patient. This is a concrete “antidote” against two possible risks: on the one hand, an excessive medicalization of the dying process in the elderly (which can result in a so-called “aggressive medical treatment”); and on the other hand, a lack of care – considering the elderly patient practically “lost” for medicine and without meaning and hope – which can result in the elderly requesting euthanasia.

Social freezing, older mothers and the welfare of the child

Pennings, Guido

Guido.Pennings@ugent.be

Introduction: One of the most criticized instances of medicalization in society today is ‘social freezing’. Social freezing refers to women who at a relatively young age decide to freeze their eggs in order to maintain their chances of having genetically related children in the future. Many people argue that instead of looking at medicine for a solution, we should modify societal rules in order to enable women to have their children at a younger age. Although there are numerous objections to social freezing, we will concentrate here on the welfare of the child.

Central research question: Is there evidence that children of older mothers are worse off than children of young mothers and if so, according to which standards are these findings evaluated?

Results: There is very little empirical evidence on the welfare of children born to older mothers. However, it is clear from the present debate that the criterion ‘welfare of the child’ is evaluated with different standards by different authors. In our discussion, we distinguish between a personal and an impersonal standard. Both standards have a comparative and an absolute version. Finally, we distinguish between a sufficientarian rule (reproduction is acceptable when the child has a wellbeing above a threshold) and a maximizing rule (reproduction is only acceptable when the child has the highest wellbeing) (notice that the

non-identity problem does not muddle the water in this comparison). We will illustrate these standards within the context of social freezing.

The lack of empirical evidence on the welfare of children of older mothers has brought people to turn to parental characteristics as ‘markers’ of child wellbeing. Characteristics such as old, physically weak, etc. are used to suggest parental incompetence and thus lower child wellbeing. Again, the link between these elements is weak. Nevertheless, this line of reasoning reveals one common feature of the ways this question is looked at: the extreme reduction of the context. The reduction is shown in the following points: the woman is one-dimensional (old without other characteristics); the woman is the sole parent; the (possible) changes between time of freezing and later use are ignored; and, the exclusive focus on the welfare of the child. The most likely way to avoid this reduction is to move to a personal standard; in other words, leave the decision on the acceptability of parenthood to the parent(s).

Conclusions: The different standards for the evaluation of empirical findings regarding welfare of the child allows people to adopt the standard that best fits their moral intuition. Therefore, the discussion on social freezing should include a discussion on the appropriate use of the standards.

Do right and fear no one? Family physician and cancer screening, an ethical perspective.

Piessens, Veerle; Christiaens, Thierry; Devisch, Ignaas; De Sutter, An
veerle.piessens@scarlet.be

Background: Cancer screening is strongly promoted, both by government and medical authorities. Almost every (industrialized) country has a screening program for breast cancer and cervical cancer. Some countries have programs for colorectal and prostate cancer. And trials are going on to examine the effect and feasibility of screening for melanoma, ovarian cancer and lung cancer.

Nevertheless there is much debate about cancer screening. Sometimes the debate becomes an aggressive polemic, e.g. the mammography-controversy that peaked after the publication of the paper “Is screening with mammography justifiable” in The Lancet in 2000.

Very often the family physician is expected to play an important role in cancer screening. If not for organizing or doing the screeningprocess itself, than at least the family physician is expected to encourage his patients to participate in cancer screening. Among family physicians, opinions are divided: some claim a central position in cancer screening, others refuse it and say it would distract them from their core-business, which is to deal with the health-problems their patients consult for. The on-going debate makes it for a general practitioner difficult to know what is in his patients interests and what strategy should be used in daily practice.

Question: Can using an ethical perspective on cancer screening help a general practitioner in adopting a policy in screening that is balanced, fair and sustainable.

Method: In this paper family physicians actions and decisions in cancer screening are discussed within an ethical framework, using the 4 basic principles in biomedical ethics ‘do good’, ‘do not harm’, ‘respect for autonomy’ en ‘justice’.

Results: A lot of the fuel that feeds the polemic seems to evaporate, the different arguments are set next to each other and get the value they deserve. Cancer screening can do ‘good’ to some people: it can lower mortality and morbidity . But the risk of getting ‘harmed’ by it is also a reality: screening induces morbidity, fear and a lot of medical interventions. GP’s are in a key position, not only to inform their patients about the existence of a cancer screening

program, but also to give them balanced information about 'good' and 'harm' and support them in their 'autonomy' to decide about their own lives. Broad accessibility, long-term relationships and contextual knowledge are important features of general practice as they give the opportunity to a 'fair and just' treatment of all people.

Conclusion: Systematic cancer screening is a delicate ethical balancing act where there are more values than only 'healthgain'. A general practitioner has a particular role and responsibility in cancer screening and using an ethical framework helps the GP in finding a balanced, sustainable and fair strategy.

The concept of medicalisation: A critique

Podmore, Will

W.Podmore@bso.ac.uk

Early in Ivan Illich's 1976 book, *Limits to medicine*, he revealed his methodology: "Some footnotes document the information I have used to elaborate and to verify my own preconceived paradigm for optimally limited health care ..." He used evidence to support his preconception – an unscientific procedure.

Illich opened the book with the claim that "the medical establishment has become a major threat to health. ... the damage done by medicine to the health of individuals and populations is very significant." He gave no figures to back these claims. The ills he pointed to were due to the rule of the market, especially so in the USA.

Research has proved that generous provision of acute care improves health and reduces mortality. By claiming falsely that medicine and health care did not and could not improve people's health, Illich was advocating laissez-faire politics.

Illich generalised from this flawed study of 'clinical iatrogenesis' to what he called 'social iatrogenesis'. Here he complained that through what he called the 'medicalisation' of everything - birth, life and death – "health care has become a monolithic world religion ..." He railed against what he called one of the French Revolution's two great myths, "that physicians could replace the clergy." Illich was of course a Catholic priest.

Illich's term 'medicalisation' has not been widely accepted. It does not appear in the Oxford English Dictionary, medical dictionaries, or standard texts on medical ethics.

Then he deplored what he called 'cultural iatrogenesis', 'the transformation of pain, impairment and death from a personal challenge into a technical problem'. He stated, "Morbidity and mortality are an integral part of the human environment and unrelated to the efforts made to control any specific disease." Here he was advocating that we are born to suffer, the dogma of original sin.

He claimed, "only a political programme aimed at the limitation of professional management of health will enable people to recover their powers for health care." He concluded, "The true miracle of modern medicine is diabolical. It consists in making not only individuals but whole populations survive on inhumanly low levels of personal health."

The marketisation of health care, not the 'medicalisation' of life, was the problem. Illich's flawed analysis led to his attacking the wrong targets, the medical profession and national health services, led, that is, to reactionary politics. He called for the end of health services and the end of welfare states. In his book on education, *Deschooling society*, he called for the end of public, secular education.

Illich endorsed the ideas of extreme reactionaries like Milton Friedman, writing, "A logical way of cutting the budget and, one hopes, of increasing benefits is a system of tuition grants such as that proposed by Milton Friedman and others." Unsurprisingly then, US libertarians

in turn backed his ideas. Leonard Liggio in the *Libertarian Forum* enthused, “Illich wants to eliminate the tax support for the schools as well as health, welfare ...”

The biomedicalization of public health risk: Exploring the ethical dimensions of human papillomavirus (HPV) vaccination through a discursive narrative approach to parental decision-making

Polzer, Jessica

jpolzer@uwo.ca

As a form of medicalization, human papillomavirus vaccination (HPVV)²⁷ is unique in that it does not demarcate a new category of sexual abnormality or dysfunction that can be treated with pharmaceutical or medical intervention; rather, HPVV designates the emergence of “normal” sexual relations as a time that is fraught with *risk* for cervical cancer. Furthermore, HPVV bypasses the need to detect corporeal risk through the physical examination of bodily tissue (e.g., cervical cell smears), focusing rather on harnessing the (female) child’s biological potential to “fight” against sexually transmitted infection that may lead to future disease²⁸.

As a pre-emptive approach to risk management, HPVV produces and governs the child’s “risky” body, and cradles her emergent sexuality, within a complex matrix of power relations involving the State, the pharmaceutical industry, the medical profession, and intimate relations. HPVV places responsibility for cancer prevention primarily on parents who are expected to vaccinate as a way to demonstrate their moral obligations to protect the health of their children, as well as the health of those with whom their children develop intimate relations.

Drawing on biomedicalization theory²⁹ and Foucauldian notions of biopower and ethics, this paper will focus on the ethical relations that surface in the context of this constellation of power relations. This focus on the ethical dimensions of HPVV will be grounded in interviews conducted with parents who accepted, declined or are considering HPV vaccination for their daughters and/or sons. A discursive narrative methodology adapted from previous research on young women’s decision-making about HPVV³⁰ will be used to illustrate how parents navigate their decisions about HPVV, and construct themselves as responsible citizens, in relation to discourses on gender, sexuality, and responsibility for (sexual) health. The decision-making narratives will illuminate how parents: (i) reproduce and resist dominant cultural scripts concerning cancer, sexuality, and gendered responsibilities for (sexual) health; (ii) negotiate their children’s risks for future cancer and their “risky” bodies in relation to their own personal experiences related to cancer, sexuality

²⁷ In Canada, HPVV is approved for both males and females aged 9 to 26, but is covered by public health insurance only for girls aged 9 to 13 in most provinces and territories. The rationale for initiating the three-dose vaccine within this age range is based on evidence suggesting that efficacy is greatest prior to onset of sexual relations.

²⁸ Polzer, J. & Knabe, S. (2012). From desire to disease: Human papillomavirus (HPV) and the medicalization of nascent female sexuality. Special issue of the *Journal of Sex Research* on the Medicalization of Sex, 49(4), 344-352.

²⁹ Clarke A, Mamo L, Fosket J, Fishman J, Shim J. Biomedicalization: Technoscience Health and Illness in the U.S. Durham, N.C.: Duke University Press; 2010.

³⁰ Polzer, J., Mancuso, F. & Laliberte Rudman, D. (2014). Risk, responsibility, resistance: Young women’s negotiations of identity and healthy citizenship in human papillomavirus (HPV) narratives. *Narrative Inquiry*, 24(2), 281-308.

and gendered responsibilities for (sexual) health; and (iii) construct themselves as responsible parents in culturally-specific ways that reflect their intersecting social identities and locations.

Palliative sedation and euthanasia

Raus, Kasper

Kasper.Raus@ugent.be

An end-of-life practice that has received considerable attention in the last decade is the practice labelled as continuous, palliative or terminal sedation. This practice roughly involves intermittently or continuously sedating a patient until death in order to relieve her suffering. For this presentation I shall focus on continuous sedation, which is the more far-reaching form of sedation. Though far-reaching, continuous sedation is widely considered to be less ethically controversial than euthanasia or physician-assisted suicide, as it is said not to involve intentionally killing a patient and to allow a natural death. Various national and international guidelines describe why and when the practice is justified and how it should be performed. Research also shows that continuous sedation is widely used in Belgium, The Netherlands and the UK.

Quantitative and qualitative studies performed in The Netherlands, Belgium and the UK provide valuable insights into how the practice is used in these countries. Available research indicates that there are considerable differences between these countries in the ways that continuous sedation is defined, perceived and performed. In this lecture I will discuss how continuous sedation is performed in Belgium and how this compares to UK and Dutch practice. For the comparison between the three countries, I will rely on the results of a qualitative study (2011-2013) in which I have been actively involved (the UNBIASED study), comprising in-depth interviews with Belgian, Dutch and UK physicians, nurses and bereaved relatives.

In my presentation I shall highlight some of the most relevant differences between the UK, The Netherlands and Belgium. There exists considerable difference in the way in which the practice is labelled in communications with patients. There are also different approaches to proportionality (i.e. the criterion, emphasised in various guidelines, that the sedation should be proportionate to the patient's symptoms). Finally, in the UK, The Netherlands and Belgium, respondents exhibit differences in reported intentions. The Belgian practice of continuous sedation at times appears to be much more similar to euthanasia than the UK practice. Some Belgian physicians and nurses report a co-intention to shorten life. In Belgium, patients are at times deeply sedated with no intention to wake them up again, and medical staff sometimes organize an official goodbye moment for relatives just before sedation is initiated. This may raise concerns about whether Belgian physicians are using continuous sedation as a way to avoid the administrative hurdles surrounding euthanasia. UK physicians and nurses often described a more gradual process and lower dosages of drugs. Also, they were adamant in denying an intention to shorten life or even an intention to sedate. Finally, the presented data clearly raise ethical questions and thus invite ethical reflection. In the final part of the presentation, I would therefore reflect on the practice of sedation in the UK, The Netherlands and Belgium, and their relation with the more controversial practice of euthanasia.

Just food: Changing the culture of possibilities to promote health

Rawlinson, Mary C

mary.rawlinson@stonybrook.edu

The US Center for Disease Control estimates that one in four adults and one in five children in the US are obese. Global agribusiness currently targets Low and Middle Income Countries (LMICs) as new markets. While infectious diseases in LMICs are declining rapidly, obesity-related diseases are spiking.

Policies addressing the global obesity crisis focus on individual responsibility and medical interventions, while ignoring *the dependency of human agency on a culture of possibilities*. The emphasis on personal choice and medical management elides the structural determinants of eating habits, at the same time that it deflects the political strategies and collaborations necessary to install and sustain infrastructures adequate to the just production and distribution of wholesome food.

The dichotomy between individual choice and state paternalism that dominates food policy debates is doubly misleading. On the one hand, the focus on individual responsibility operates under a fiction of liberty. In High Income Countries (HICs) agribusiness controls markets and imposes poor food options directly related to the epidemic of obesity and obesity-related diseases. On the other, while isolated state bans on certain products are unlikely to remake the culture of possibilities that determines how people eat, these bans do not represent a new intrusion of the state into the domain of food. For decades policies in the US have favored industrial agriculture over local sustainable farming. Many HICs have been complicit with agribusiness in shaping culinary practices and norms to favor global processed food over healthier local alternatives.

The focus on medical intervention impedes the structural reforms that are necessary to insure the availability of wholesome food, at the same time that it substitutes expensive, invasive treatments for more effective strategies in nutrition and exercise. Saudi Arabia, for example, currently suffers an obesity crisis among women that is directly related to the immobility imposed on them. In 2009 the Kingdom closed all gyms to women, who are also confined by dress codes and prohibitions against appearing outside the home without a male guardian. Obese women are shunned and held responsible for their condition, at the same time that they have little agency to address their plight. Recourse to bariatric surgery has become common and substitutes for an analysis of the way in which their obesity reflects the culture of possibilities in which they live.

Similarly, in the US obesity is addressed as a medical problem, rather than a reflection of culture and structural inequity. While obesity is directly related to poverty and to 'food deserts' where fresh, wholesome food is unavailable, public policy relies on medical intervention, rather than structural change. The National Bureau of Economic Research estimates that medical treatments for obesity cost 168.4 billion a year; yet, there has been little effort to change policy to favor wholesome food over the interests of agribusiness or to promote home cooking and exercise as effective interventions.

My paper argues for promoting health by changing the culture of possibilities to serve human beings, rather than the economic interests of global agribusiness and medical intervention.

Between medicalization and de-medicalization of wishing to die

Rehmann-Sutter, Christoph; Gudat, Heike; Ohnsorge, Kathrin; Streeck, Nina

rehmann@imgwf.uni-luebeck.de

At the end of life, the reception of patient's wishes to die influences whether they are respected and included in further decision-making, or treated psychiatrically as a symptom of a depression, in order to make them disappear. Reflecting on results from empirical work on the phenomenon of wishes to die in palliative care patients, we will discuss the ethical question, whether wishes to die should be respected as such or need treatment in order to alleviate them. If the authenticity and the relative constancy of a wish is established, it is still a matter of interpretation whether a given wish to die is a symptom, which covers an underlying wish to live (against the belief of the person who wishes) or an expression of the patient's "true" will.

Using the conceptual framework of Miranda Fricker's 'epistemic injustice', medicalization (pathologization) and de-medicalization of wishing to die can be a form of both testimonial and hermeneutic injustice: A wish to die is either not respected just because it is actually a wish to die, or it is interpreted as being an expression of its contrary, namely a wish to live. Both forms of social perception of wishing to die at the end of life do not justice to the patient's subjectivity. But there may also be an injustice on the other side of the spectrum: If a wish to die is just taken at its face value and not questioned, there is a danger of misinterpreting wishes to die, which actually are symptoms of a crisis that could be resolved by other means. This would be a (radical) de-medicalization of wishing to die, and then also a hermeneutical injustice that wrongs the patient, since the provision of assisted dying may not be *ultima ratio*.

With these considerations we hope also to contribute to a clarification of the concept of medicalization. We suggest that it should be taken as a critical moral description of a change in medical practice that classifies parts of this practice as lacking true medical meaning. We argue in favour of a communicative practice in end-of-life care that avoids both medicalization and (radical) de-medicalization.

A discussion of wishing to die is difficult because partners in the discussion may be affected by its subject. Psychoanalyst Melanie Klein has described 'defended subjects': Wishing for death (instead of fearing or fighting it) can threaten the self at a largely unconscious level. This might be true for the patient and relatives, but it may also be true for healthcare professionals – and for us as bioethicists.

Responding to vulnerabilities of so-called "difficult" patients

Rentmeester, Christy

christyrentmeester@creighton.edu

In the United States, patients suffering mental illnesses who struggle to manage their behavior in socially and culturally acceptable ways during clinical encounters are often labelled as "difficult" by professional caregivers. This labelling is an ethically and clinically problematic expression of medicalization that pathologizes patients already disadvantaged by mental illnesses. I describe and analyze different dimensions of ethical issues related to professionalism in these kinds of common cases. While my experience is in the context of mental healthcare ethics in the United States, many of the points I will consider about so-called "difficult" patients can be readily applied internationally. Specifically, acknowledging the roles of complex moral and emotional experiences in countertransference, such as anger and fear, is important for all mental health clinicians. Such emotions can contribute to the

phenomenon of legalism in healthcare, a practice informed by an imagined legal point of view that seeks to protect the clinician but rarely protects the patient. Legalism can undermine the therapeutic capacity of the clinician-patient relationship in mental health practice. I describe and analyze different dimensions of legalism and suggest strategies for how clinicians can respond to so-called “difficult” patients in ways that preserve a patient-centered focus in mental health.

Discourse biogerontology. Starting a public discourse by teaching bioethics

Rheinsberg, Zoé; Ehni, Hans-Joerg

zrheinsberg@web.de

Advancements in biological aging research (biogerontology) have shown that age-related diseases may be combatted more effectively in the future by directly intervening into the aging process. This prospect is associated with hopes for solving problems of demographic change as well as complex ethical, legal and social issues that have hardly been a topic of discussion to date. Therefore, as part of the project an interdisciplinary discourse module entitled “Ethics of Biogerontology” that focuses on competence and argumentation skills was developed with experts from the relevant disciplines (biogerontology, social gerontology, philosophy, geriatrics, and medical ethics). This module was tested in eight discourse teaching projects in research, medicine and education. The classes have been being tested in various partner institutions and evaluated based on an ethical competence model. We will present the main results of this project: conception, content, teaching methods, and experience with teaching the modules in different institutions.

Erectile dysfunction medications – Therapy, enhancement or solution in search of a problem?

Robeson, Richard

rich.robe@northstate.net

A recent television advertising campaign in the United States features an attractive middle-aged woman alone in her bedroom, pointing out that women would prefer to “curl up with their favorite man” rather than their “favorite book,” after which she extolls the virtues of the erectile dysfunction (ED) drug, Viagra®.

Even though erectile dysfunction — impotence in its non-market based designation — is sometimes associated with biomedical syndromes, adverse reactions to or side effects of certain medications, therapies, or physical injury, it is generally understood that ED is in most instances less a steady-state disorder or “illness” than a situational or “occasional” anomaly in the majority of instances in which ED presents, not least among them being less-than-optimal levels of overall fitness.

The advertising campaign referenced above, which has counterparts with the two other high-profile ED drugs, Cialis® and Levitra®, encourages the suspicion that either their sales or their stock prices haven’t met expectations in recent reporting cycles. According to a February 2015 article in Canada Journal, for example, sales of Viagra® fell 8 percent in 2014.

ED drugs offer an intriguing line of inquiry into the therapy-enhancement dichotomy. The discovery of a priapismic side effect of a medication meant to treat hypertension has led to a multi-billion-dollar-per-year industry to “treat” a condition that appears to be as much about marketing as medicine, as the side effect became the essential cause of a medical diagnosis.

Or, a solution — itself a condition requiring medical intervention if, as stated in the warnings and disclaimers, the drug's now-intended effect lasts longer than four hours — became a target condition, from which the drug's discoverers appear to have worked backward to arrive at a problem.

This paper argues that the medicalization of ED raises interesting questions concerning the intersection of therapy vs. enhancement, marketing and ethics, in part because the above-referenced advertising campaign seeks to create patient demand by first creating (or perhaps regaining) patients: encouraging a middle-aged woman to in turn encourage her significant-other to become a patient (or “health care consumer” in contemporary parlance) in a drug regimen whose preeminent value seems ultimately to have been its novelty, which has since worn thin, to the detriment of sales, profit and stock valuation. The same Canada Journal article points out that in only three years, generic versions of Viagra® will be available, and that this is also a factor in the alarm evidenced by the current surreptitious patient-creating ad campaign. Perhaps novelty (and new marketing possibilities) will rejoin the conversation, however, as there is renewed attention to research findings published in 2010 in *The Journal of Sexual Health* (Nunes, et al) involving the venom of the Brazilian Wandering Spider, the most powerful spider venom known, and which also has priapismic side effects, by different processes.

Understanding overdiagnosis as a form of medicalisation

Rogers, Wendy

wendy.rogers@mq.edu.au

There is growing international concern about a form of medicalisation known as ‘overdiagnosis’, involving healthy individuals being labelled with specific diseases. In overdiagnosis, the diagnosed condition is not currently a harmful disease, and will not progress to harmful disease during the life of the patient. Many examples have been documented, such as the overdiagnosis of various forms of cancer (e.g. breast, prostate, lung, thyroid), mental illnesses such as depression or attention deficit hyperactivity disorder, and conditions that may be considered risk factors, such as elevated cholesterol, blood sugar levels or body weight. There are various drivers for overdiagnosis, including: greater sensitivity of diagnostic tests; increasing use of these tests as part of “health checks”; medicolegal fears about failing to investigate potential abnormalities; widespread cancer and other forms of screening aiming to prevent advanced disease; pressures secondary to commercial interests; and intolerance of minor symptoms. Overdiagnosis comes at a cost, not only regarding harm to individuals who receive unnecessary investigations and treatment, but also in terms of the resources diverted away from urgent and necessary care into overdiagnosis.

In this paper I propose two forms of overdiagnosis, which arise in different ways. Type 1, maldetection overdiagnosis, occurs when an asymptomatic individual is diagnosed with a disease based upon the result of a biomedical test. The test result is positive, yet not all of those individuals with a positive result will go on to develop harmful cases of the disease in question. This means that following the diagnosis, a proportion of people will receive unnecessary treatment (sometimes including chemotherapy or surgery). Type 1 overdiagnosis arises because the test fails to discriminate between harmful and harmless cases; that is, it has an epistemic source.

Type 2 overdiagnosis, misclassification, occurs when diagnostic thresholds are set at levels such that many people are considered to have a positive diagnosis for disease despite the absence of symptoms and/or harm. Type 2 overdiagnosis blurs two distinctions. First, it blurs

the distinction between risk factor and disease, leading to large numbers of people being diagnosed with conditions such as type 2 diabetes or chronic kidney disease when their risk of disease is very low. Second it blurs the distinction between disease and the normal discomforts or experiences of life, leading to medical diagnoses in people who grieve following bereavement, have twitchy legs or in children who are particularly active. Misclassification overdiagnosis arises as a result of intentional decisions to define the boundaries of disease in one place rather than another rather than reflecting an epistemic gap. These distinctions help to explain what overdiagnosis is and how it arises, and thus can inform strategies to limit this particular form of medicalization.

Procreative choices and alternative concepts of harm

Rozynska, Joanna

j.rozynska@uw.edu.pl

Like many people, I have a strong moral intuition that parents, who risk or decide to bring into the world a child under significantly disadvantageous condition (even if it is not so terrible *as to make the child's life not worth living*), harm the child. But this “harm to the child” intuition is hard to justify if the concept of harm is interpreted in a standard, counterfactual way. According to the standard account of harm, “to be harmed” means to be made worse off. A person *B* is harmed if in a consequence of an act *x* of a person *A*, *B* is in a worse condition that she would otherwise have been if person *A* had not acted *x*. This concept of harm has four important features – it is evaluative, comparative (via counterfactual test), identity-“sensitive” (as it indicates the comparative value of two states of affairs for one and the same individual), and aggregative (meaning, it determines harmful or beneficial impact of a given act according to the overall, all things considered effect that act has on the individual’s level of well-being). This concept of harm is widely used in law and ethics. However, when applied to reproductive choices, it gives rise to two theoretical puzzles: the *non-identity problem*, described over twenty five years ago by Derek Parfit, and the *non-existence problem*, being a core of so-called “wrongful life” cases. Both these problems show that the standard concept of harm leads to moral conclusions which conflict with our commonsensical moral intuitions concerning what we owe to our (future) children.

The aim of this presentation is to explore a possibility of finding a theoretical justification for the “harm to the child” intuition between Scylla of the non-identity problem and Charybda of the non-existence problem. I will argue that we can find such a justification (although only partial), if we redefine the concept of harm. I will analyse five alternative accounts of harm: [1] identity “non-sensitive”, *trans/impersonal harm* (Glover, Brock, Peters), [2] non-comparative, *absolute harm* (Parfit, McMahan), [3] non-comparative, *harm based on rational preferability* (Feinberg), [4] non-aggregative, *prima facie harm* (Harris, Shiffrin, Harman, Benatar), and [5] *threshold harm* (Morreim, Meyer, Cohen, Green, Purdy). I will claim that the last concept may provide theoretical basis for the “harm to the child” intuition. According to the threshold interpretation of harm, an act *x* harms someone only if the agent thereby causes this person's life to fall below some specified threshold. This interpretation of harm, when applied to reproductive choices, presupposes our being able to lay out a standard of well-being in such a way that we harm a child when we bring her into existence in a condition that falls below the standard. Specification of such a standard is, of course, a complex and difficult issue. The threshold must be sensitive to social and cultural context of reproductive decisions, and – probably – based on some justice considerations. Discussion on justice in reproductive ethics is however beyond the scope of this presentation.

On making a diagnosis

Sahm, Stephan W

s.sahm@ketteler-krankenhaus.de

Diagnosis is one of the key concepts in medicine. Yet, it seems to be not as clear a concept as it is thought to be in medical practice. At a first glance, it is held that there is a causal relation to illness and disease. In particular in the sphere of what is regarded as the medical model such a connection is thought to be fundamental. Yet, the analysis shows that diagnosis are not diseases, or more precisely, the connection of diagnosis to diseases/ illnesses is shown to be a cultural construct.

In this paper I will show that to diagnose is equivalent to *decide* about a condition to be called a disease/ illness as opposed to detect or delineate something. This conclusion may be illustrated by the phenomenon of overdiagnosing which is pervasive in modern medical practice. Hence, to diagnose denotes the point where physicians stop constructing causal relationships in favour of acting on patients (or persons held to be patients). The mere fact of diagnosing is an act on patients - even if it is not followed by any specific medical treatment. As these concepts (i.e. of diagnosis, disease etc) are placed at the centre of practicing medicine they guide “medical” conduct and, hence, are of direct ethical relevance. The epistemological basis of these notions has to be considered properly, if we try to improve medical practice.

Inevitably, the concept of diagnosis (as well as that of health) cannot escape from being only *understood* while being *not defined*. This refers to Hans Georg Gadamer’s sentence with respect to disease, illness and health and which also applies to the notion of diagnosis: These are notions *in seclusion* (Verborgenheit).

Nevertheless, life asks us to react to conditions we encounter in other persons we think to be patients. And there is evidence that we are able to react appropriately. Everybody who ever saw an ill or diseased person is aware of it. Such a situation unfolds a certain kind of authority, which forces us to act. And there is no infinite time to analyze all the relevant medical, biological and social (and whatever) aspects. The limitation to take into account any aspect (molecular, physical, psychological, sociological, spiritual) of a patient’s condition signifies the point where the so-called medical model finds its limitations. Rather, the fact of making a decision if making a diagnosis reveals that to diagnose is a normative act.

This paper will present a hermeneutical view on medical practice. It will consider latest developments like genetic chip cards or modern imaging techniques. The ethical implications of that view will be outlined with respect to modern, medical technology.

Is uterus-transplantation an example of an unwarranted medicalization that should not be funded within a public health-care system?

Sandman, Lars

Lars.Sandman@hb.se

In September 2014 a research team at Sahlgrenska University, Gothenburg succeeded in bringing a uterus transplantation to a successful pregnancy and birth of a child. Uterus transplantation raises a number of ethical and philosophical questions about acceptable risks, the limits of medicine, the right of having children, the identity of the child (given being born through the uterus of a grandmother or an aunt etc.) etc. (Caplan, Perry, Plante, Saloma, & Batzer, 2007; Catsanos, Rogers, & Lotz, 2013). It also raises questions about whether this is an unwarranted medicalization that should not be funded within a public health-care system,

or a bit weaker that should not be prioritised in situations of austerity (Johansson and Sahlin 2011).

In this discussion, the case of uterus transplantation seems to be treated as a special case of medical development and for that reason does not warrant resources in routine health-care. In this presentation I will analyse uterus transplantation from a medicalization and priority setting perspective, ignoring any other ethical problems there might be with this intervention. Given we accept medically assisted reproduction in other forms (for example IVF) – uterus transplantation would seem to be based on a similar patient need, have similar patient benefits and moreover, have a definite medical problem (a non-functioning uterus) as cause of the patient need. Based on this, uterus transplantation does not seem to be a radically new step towards medicalization or with specific priority setting problems. At the same time, it can be argued that a massive surgical intervention with resulting need of immunosuppressive drugs for only quality of life needs is at least partly a step towards medicalization. Moreover, it can also be questioned if the patient need in question is great enough to warrant such a massive intervention. In the talk I it is argued that this is dependent upon which alternative treatments we accept. Paradoxically enough we might find ourselves in the situation where it will be difficult to resist the patient need for uterus transplantation if we resist surrogacy (which might be a more radical step towards medicalization). On the other hand, if we accept surrogacy, we will have fewer reasons to accept uterus-transplantation (given the added patient need of bearing a child).

A tentative conclusion is that uterus-transplantation does not imply a radical step towards medicalization. Instead it can, paradoxically enough, fulfil an accepted patient need and thereby avoid, what can be seen as a, more radical step towards medicalization, i.e. surrogacy.

References:

- Caplan, A. L., Perry, C., Plante, L. A., Saloma, J., & Batzer, F. R. (2007). Moving the womb. *Hastings Center Report*, 37(3), 18-20. doi: 10.1353/hcr.2007.0036
- Catsanos, R., Rogers, W., & Lotz, M. (2013). The ethics of uterus transplantation. *Bioethics*, 27(2), 65-73. doi: 10.1111/j.1467-8519.2011.01897.x
- Johansson, M., & Sahlin, N.-E. (2011). When technology goes astray. [När tekniken går vilse.]. *Läkartidningen*, 108(26-28), 1348

Is human enhancement good for us? And if so, in what way?

Schermer, Maartje

m.schermer@erasmusmc.nl

Over the last decade the debate on human enhancement technologies has flourished, perhaps even more so than the technologies themselves. Biomedical enhancement - understood as using biomedical means and technologies to enhance certain functions or traits of human beings - includes technologies and practices as diverse as doping in sports, cosmetics surgery, some forms of assisted procreation, pharmacological cognitive enhancement and (hypothetical) moral enhancement.

Proponents of enhancement assume that enhancement will be good for us, “because otherwise we would not call it enhancement.” Or so the rather circular argument for this goes. But building the condition that it will improve our well-being into the definition of enhancement itself, as welfarists such as Savulescu do, does of course not answer the central question: which enhancements of human functionings or traits are indeed conducive to well-being?

So far, there has been remarkably little debate on the issue of the supposed ‘good’ of enhancement. When considering the literature it appears as if most emphasis has been on the individual good that enhancements might bring. These can be subdivided in positional goods (those goods that give one a competitive edge, an advantage over others, like speed in a athletic competition) and intrinsic goods (things that are good for you regardless of what others have, like knowledge, or love). Problem with only focusing on individual good is that sum of individual goods need not necessarily be good for all of us. It need not increase overall well-being, and need not be conducive to the common good.

I propose that human enhancement should be evaluated in light of the common good, and I will explore whether and if so, how, human bio-enhancement can indeed contribute to that. Following Buchanan, we might see enhancement as a form of human development, and for example understand pharmacological cognitive enhancement in line with historical improvements like written language, electronic calculator and the Internet. Or we might claim that bio- enhancement will improve economic productivity and hence well-being; or that it will enable scientists and technologists to help solve the problems the world faces.

All these claims can be criticised, of course, and examples of negative effects of enhancement on our collective well-being can be given as well. The overall judgment of whether bio-enhancement is ‘good’ for us is therefore likely to be very complicated and dependent on context and the specific technology under consideration. But taking the common good as a starting point in thinking about the desirability of developing new human bio-enhancements will hopefully enhance debate and policy in this exciting field.

Medicalization in psychiatry: Recovering lost knowledge

Sedler, Mark J

Mark.Sedler@stonybrookmedicine.edu

The medicalization of mental illness has been the object of critical analysis at least since the publication of Thomas Szasz’ *Myth of Mental Illness* (1961). The “anti-psychiatry” movement that followed was supported by the pivotal works of the psychiatrist R.D. Laing (*The Divided Self*, 1960), the sociologist Erving Goffman (*Asylums*, 1961), and the philosopher Michel Foucault (*Madness and Civilization*, 1961). These analyses illuminated the fallacy of confusing bad behavior with a bad brain, the problem of distinguishing the normal from the pathological in mental life, the effects of institutionalization on behavior, and the exercise of power on marginalizing and containing psycho-pathology.

Many of these objections to a categorical disease ontology remain valid, but have been mostly forgotten in a strategic effort at collective amnesia precipitated by the wholesale embrace of biological therapies and dogmatic neuro-scientism. The DSM-V continues to serve this enterprise, even as the original goal of reliability and an awareness of its limited validity is obscured by the failed ambition for paradigm change. While the medical impetus for this effort derives in part from a genuine search for effective therapeutics, as well as frustration with the intangible results of much psychological research, clinical practice is now inextricably intertwined with the economic interests of health insurers and the commercial pharmaceutical industry. As a result, psychiatric practice today in the U.S. has been reduced largely to diagnosis according to DSM-V and treatment guidelines that consist primarily of pharmacologic algorithms.

As a result of this model and the procrustean role of “medication management” sanctioned by managed care, newly minted psychiatrists are increasingly narrow in their approach to patients. Every symptom is viewed as a potential target for drug treatment, and few other options, e.g. doing nothing, are considered. While training gives lip service to

psychotherapies such as cognitive-behavioral treatment, few psychiatrists actually employ such methods, which themselves are sterile by-products of the new scientism. Even fewer young psychiatrists have by dint of aptitude, training, or inclination an existential perspective that might facilitate alternative understandings of patient's experience and a more nuanced clinical approach.

A frequently unrecognized side effect of the psychoanalytic project in psychiatry as a discipline was its hermeneutic interest in virtually all domains of knowledge. In a relentless quest for windows onto the operations and contents of psychic life, psychoanalytic psychiatry extended its reach to all branches of the social sciences and humanities. As a consequence of its failure to assimilate modern discoveries in biological treatment, psychoanalysis became a casualty of the biological psychiatry movement, a forfeiture of knowledge signified by the early abandonment of the term "neurosis" in DSM-III (1980).

A psychiatrist who is conversant with the social sciences and humanities, and who tempers materialism with a more comprehensive metaphysics of the psyche, is increasingly rare. It remains to be seen if this broader understanding of human experience will be lost permanently, or whether a dialectical correction within psychiatry can redress its current scientism. My paper argues for a return to this essential, but repressed philosophical knowledge.

Medicalising family "imbalance": an ethical critique of sex-selection

Shahvisi, Arianne

arianneshahvisi@outlook.com

At the start of 2015, a bill was debated in UK parliament, which promised to make sex-selective abortion illegal. While the bill was eventually rejected, the driving concern is no doubt substantive. Though it is primarily associated with particular cultures and locations, son-preference is a damaging global phenomenon, and derives its force from the patriarchal hegemonies in which we live. Most interlocutors agree that selecting the sex of one's child for non-medical reasons is not morally defensible, though many readily claim, without further defence, that sex selection is acceptable in the case of "family balancing." That is, it is commonly seen as defensible for the medical profession to assist a family in choosing the sex of their next child, provided the sex-distribution of existing offspring is "unbalanced." In those cases, "imbalance" carries a negative valence, and so medicine is called upon to address this imbalance—as it does bodily imbalances—as though the family, and its gendered aspirations, were a diseased organism. Apart from the obvious intuition that something has gone awry in well families becoming the subjects of medical interventions, I present four serious and novel concerns with the idea that sets of children must be "balanced" in this way as a matter of medical urgency. First: there is an obvious subjectivity about precisely what the term "balance" might entail, and which ratios are most likely to be construed as imbalance and acted upon. Second: it is not clear why sex is being privileged as a site of imperative balance, rather than other physical or mental properties. If we permit balance along one axis, how many others must we permit balance along, and where will that take us? Third: using sex-imbalance in this pejorative way to demand "balance" from sibling-groups will likely imply that families in which the parents' sexes are imbalanced are also negative in some sense. Therefore medical participation in "family balance" may entrench homophobia and further normalise heteronormative nuclear families. Fourth: since parents seeking sex-balance are more probably seeking gender-balance, there is a serious concern about how such parents would respond to trans-children who threaten to disrupt their "balanced" family. In light of these concerns, and in addition to some of the more obvious issues raised in Wilkinson

(2008), I conclude that sex-selection for the purpose of family balancing is not morally acceptable. As such, when the medical profession assists in granting these morally questionable requests, it transcends its remit, and medicalises families in the service of entrenching societal heteronormativity. Wilkinson, S. (2008) Sexism, sex selection, and 'family balancing.' *Medical Law Review*, 16, pp. 369-389.

Is the biomedicalisation of personal genomics an advance or is it retrogressive?

Shandera, Wayne Xavier

shandera@bcm.edu

Personal genomics allow for a vastly enhanced scientific understanding of an individual's constitution. The advantages include a potential for a greater popular understanding of genetics, recognition of hidden traits or disease states, and identifying unrecognized personal relationships. The disadvantages include an overemphasis on the scientific state of man, a potential misunderstanding interpreting large amounts of available data, and a fear that data may impair insurability, lead to discrimination, or uncover buried family or personal secrets.

Is it more important that personal autonomy be preserved and that new findings be sequestered or should data become widely available? Do the benefits of exposing new findings outweigh the consequences of such exposure? Does the presence of a new set of institutions, the personal genomic services, products of the corporate economy, evoke a further institutionalization of medicine? Ivan Illych recommended a deinstitutionalization (of education, medicine) in the hope that society would revert to more humane institutions and thus it may be argued that these new institutions are a step backward.

Do the personal genomic services which collect data on traits and behavior necessarily lead to better medicine and a better society or is the end product the generation of data for the genomic agencies and the financial and social success for the founders and directors of the organization? Is it not possible that the public is being rendered a victim of personal genomic services who use data for their own financial advantage and publication of findings? Is there an alternative to the generation of large volumes of often poorly understood data? One can argue that such data provides a new tool for analysis, which challenges the traditional types of medical establishment such as the doctor-patient relationship. For a short interval, 200 disease states in man were assessable by one company (until the US Food and Drug Administration ceased their operations) for less than 300 US dollars. Many Western European nations outlaw the public presence of such institutions within their local purview (although the virtual world is hard to control).

The biomedicalisation of genomics is attendant thus with advantages and disadvantages. Their ultimate impact is answered in the long term although the generation of the data is almost infinitesimally fast and increasingly available. Perhaps the most important issue is the education of the public, a time consuming process, in a way that balances sciences (so that the basic biology of personal genome services is better understood) and the liberal arts (so that the findings of science are put into a broader perspective). Society should achieve its Illychian "convivial tools" in the arena of personal genomics but this is only achievable broadly with a fundamental levels of education that are hard to achieve among the demands attendant with increasing specialization amid a public eager for instant solutions.

Ethical consideration on medical business in Japan: Genetic test and stem cell therapy

Shimoda, Motomu

shimodamotomu@gmail.com

Genetic medicine (genetic test, diagnosis and counselling) and regenerative medicine (in particular stem cell therapy) have rapidly developed and penetrated into ordinary medicine. In Japan, while genetic medicine is performed for preimplantation, prenatal and presymptomatic diagnosis, in the field of regenerative medicine clinical researches are conducted by using adult stem cells for heart and pancreas disease, or iPS cells for retina and Parkinson's disease etc.

Nowadays, the genetic test business has been expanded through the Internet for the diagnosis of predispositions such as obesity or high blood pressure, and child talent test. The stem cell therapy business has progressed from cosmetic surgery such as breast enlargement operations to treatment for diabetes or cancer by private clinics. Each expert group (academic society) has issued concerns and cautions against such business based on the lack of scientific evidence. It is also said that such genetic test business could lead people to make wrong health conducts according to inappropriate prognosis, and the stem cell therapy business has caused many problems by undesired results, which has urged the Japanese government to establish the guideline or law regulating such business.

In this presentation I would like to examine the ethical and social aspects of medical business in line with the issues of patients' freedom of choice as consumers, the quality of the information provided by the business sides, and promoting medicalisation and reductionism.

Ageing at the 21 century - Medicalisation and demedicalisation of ageing

Simonstein, Frida; Lowenstein, A

fridas@yvc.ac.il

Life expectancy has almost doubled in developed countries since the beginning of the 20th century. More people than ever survive now to their eighties and nineties; the number of centenarians has also been growing. Certainly, prolonged longevity is the successful outcome of research in the life sciences during the 20th Century: better hygiene, vaccines, antibiotics and sophisticated surgery. Undoubtedly this has been a remarkable triumph of Science.

Paradoxically, however, while prolonged longevity is generally applauded, ageing is not. Ageing is regarded as, and many times is, a frail and debilitating condition; which demands huge allocation of resources. This paper explores prolonged longevity, its value, and its discontents; the paper examines the future of ageing from the perspective of research in the life and social sciences.

A four-fold conception of disease: Infertility as a case-study

Singh, Neil

neilsingh15@gmail.com

Biomedicine is inherently normative, trading on the distinction between health and disease. However, it lacks a clear acid test by which to make this distinction. Whether a state of being constitutes 'pathology' depends not only on biological, but also social, norms—thus varying across time and between cultures. In the context of late-modern capitalism, this lack of clarity has left the formation and policing of biomedical definitions in the hands of the medical profession, in partnership with the pharmaceutical and biotechnology industries. This has

opened the door to medicalisation: the creation of new kinds of un-health, and thus new health markets, by reconceiving of normal variations in biology and social status as pathology. Which side of the health/disease divide a condition falls on is of the utmost importance and relevance to both the public and private healthcare sectors, providing potential obligations/costs and opportunities/profits to these parties, respectively. This paper examines medicalisation through a discussion of infertility, a biological variant and social condition that has widely been cast as a disease. I begin by attempting to define infertility, and then go on to discuss the ways in which infertility can be conceived of as 'harm'. Next, I review the current literature to gauge the robustness of current models of health/disease in distinguishing between health and disease, and find them lacking. I then propose a new four-fold conception of disease, comprising the following components: disorder; dysfunction; discomfort; and discordance. The most important dividing line, from the point of view of medicalisation, is that between disease and discordance. Therefore, I propose a new conceptual tool to dissect these two forms of un-health: I call this 'Hayy's Knife'. Using this tool, I find that infertility must be considered a social discordance, and not an personal discomfort. The implications of this conception of disease, for infertility and other contested conditions, are significant. By providing a way of distinguishing between 'discordance' and true disease, it allows us to create two lists of conditions: true diseases, which should then be adequately addressed by state healthcare systems; and false disease, which should never receive state sponsorship or assistance, and the treatment of which (by both public and private profiteers) should be deemed morally indefensible.

Medicalization as a boundary object

Skolbekken, John-Arne

john-arne.skolbekken@svt.ntnu.no

Medicalization has for decades been conceptualised as the transformation of non-medical problems into medical problems. More recently it has been pointed out that this conceptualisation implies a clear and given boundary between those human problems that belong to the realm of the medical profession and those that do not, whereas a more constructionist position would claim that no such clear boundary exists. The literature on medicalization demonstrates that there is a lot of boundary work going on, wherein the boundaries of medicalization are being negotiated. The first aim of this paper is to examine how various scholars approach these issues.

Part two of the examination will focus on the boundaries drawn between medicalization and the development of medicine in general. Negotiations around this issue concern the perceived fruitfulness of the medicalization framework, including claims that medicalization is now part of history, and that it has been replaced by biomedicalization. Based on the observation that pharmaceutical treatment has become an increasingly popular mode of medical treatment, the concept of pharmaceuticalization has also been introduced, representing a further challenge to the boundaries of medicalization.

Within the medicalization framework efforts have also been made to draw boundaries between medicalization and over- and undermedicalization, respectively. These efforts not only concern conceptual issues, but also imply normative challenges as their consequences are perceived to be harmful through the provision of either too much or too little medicine. The third and final part of this examination will thus also look at how various conceptualisations of medicalization reflect the coproduction of medicalization and different researcher positions.

Whole body gestational donation

Smajdor, Anna

a.smajdor@uea.ac.uk

Recently, the birth of the first baby conceived following a womb transplant was announced. Such transplants impose significant risks on live donors and recipients. Like face transplants, they occupy a problematic category in medicine and ethics, and the risks that they entail may seem more troubling than those of life-saving transplants.

Whole body gestational donation offers an alternative means of reproduction for women who lack a uterus. In 2000, Rosalie Ber wrote “. . . why not permit using the wombs of women in persistent vegetative state [PVS], female bodies kept viable by artificial means [...]?” [Ber R 2000. Ethical Issues in gestational Surrogacy. *Theoretical Medicine and Bioethics* 21:153–169.]. It seems plausible that some people would be prepared to consider donating not just their whole bodies for gestational purposes, just as some people donate their bodies for medical research, or anatomy training. We already know that pregnancies can be successfully carried to term in brain dead women. There is no medical reason why initiating such pregnancies would not be possible.

In this paper, I explore the ethics of allowing whole-body gestational donation as an optional for people signing up to the organ donor register. I consider a number of potential counter-arguments, including the fact that such donations are not life-saving, that they may reify the female reproductive body, and that they would be unreasonably costly. I suggest if we are happy to accept organ donation in general, the issues raised by whole-body gestational donation are differences of degree rather than substantive new concerns. In addition, I identify some intriguing possibilities, including the use of male bodies – perhaps thereby circumventing some potential feminist objections.

Is physician-assisted dying on its way to becoming normal medical treatment? An interview study on complex cases

Snijders, Marianne; Onwuteaka-Philipsen, Bregje; van Tol, Donald; Willems Dick

m.c.snijders@amc.uva.nl

Background and aims: In the Netherlands, euthanasia and physician assisted suicide (EAS) can be performed by a physician without prosecution, if the due care criteria laid down in the law are fulfilled. Historically, the normative base of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act was foremost the value of compassion (of the physician) and secondly autonomy (of the patient). There have been many societal developments since the enforcement of the law in 2002. A citizens’ lobby group [Uit Vrije Wil] tried to legally arrange a way to make EAS available for people who are ‘tired of living’. Right to die NL [NVVE] founded the End-of-Life Clinic [Levensindekliniek] in 2012; physicians working for this clinic are willing to perform EAS if a case has been declined by the primary physician of the patient even though it meets the due care criteria. This may lead to a gradual loss of the exceptional status of euthanasia. Ten years after the enforcement of the law, time has come to study how physicians conceive of EAS in practice. We studied the way physicians think of the moral status of requested EAS: exception or normal medicine practice?

Methods: Because we felt the issue can best be addressed in cases where EAS was seen as particularly difficult, we interviewed 30 Dutch physicians using topic-lists about their perception of complex cases of requested EAS. Through open coding and inductive analysis,

we identified different aspects of how physicians experienced the practice of EAS, with focus on the exceptional practice and conceived values.

Results: Some of the physicians stated that patients and/or family members downplay EAS and push the physician to perform EAS. Patients and/or family members who do so, attempt to overrule the personal values of the physician and even the due care criteria laid down in the law, maybe even without being aware of this. In the interviews, physicians mentioned the ongoing public debate about EAS; for instance about cases of suffering caused by dementia, about psychological suffering or about being ‘tired of living’ as a reason for an EAS request. They sometimes mentioned they experienced a ‘stretching’ of the interpretation of the due care criteria in these cases. Moreover, they wondered if being ‘tired of living’ should fall into the medical domain.

Discussion and conclusion: The various aspects mentioned in the interviews show a more general shift. According to the physicians, the value patients emphasize when requesting EAS is autonomy; they find their wish more important than the physicians’ potential moral or legal objections. The topics the public debate focusses on, show that the question at hand is no longer whether or not EAS should be permitted, but under what conditions. Both accounts of personal experiences as well as physicians’ perception of the public debate, show signs of EAS shifting from an exceptional practice towards a normal medical procedure.

Breast cancer screening in Norway through the lens of biomedicalization

Solbjør, Marit

marit.solbjor@svt.ntnu.no

Mammography screening is the primary means to prevention of breast cancer deaths in high income countries. While debates on pros and cons run high among professionals, participation rates among lay women indicate that they embrace population based mammography screening programs. One explanation to this is that it is the sensible thing to do, since early detection of cancer may save lives. A different understanding of the phenomenon is that discourses on screening are about moral obligations to self-governance of one’s health.

Klawiter (2008) has described the history of breast cancer as part of a shift. The first period was the medicalization of breast cancer. According to Klawiter, who studied breast cancer in the USA, there was a shift during the 1980s towards the biomedicalization era of breast cancer. Her argument is based on the theory of biomedicalization, as described by Clarke et al (2003). However, in Norway, the context of both breast cancer screening and breast cancer treatment is different from the US. This paper will discuss whether and how the biomedicalization hypothesis is relevant for breast cancer screening in the Norwegian context.

In Norway, the welfare state provides full coverage of health insurance, and public health services are in charge of the mammography screening programme. All women aged 50-69 years are invited to the programme biennially, and individual payment includes only a small fee. The Norwegian mammography screening programme reached national coverage in 2004. Previous research suggests that continuous participation in the programme contribute to routinization of screening, and thereby to the medicalization of society (Solbjør et al, 2014).

Though services are provided locally, national guidelines apply, and treatment options rely on evidence based medicine. Screening, diagnostics and treatment are all done through advanced technologies, including genetic testing and biotechnologies. One of the issues to be discussed in the paper is whether professionals remain in control over knowledge production, or whether the distribution and control over knowledge have become heterogeneous through

new actors. The paper will explore how advocacy groups have influenced the field. While voluntary work by and among women with breast cancer had been going on since the 1970s, the breast cancer survival association was established as late as 1992. Whether this organization has contributed to lobbying has not been previously analysed, but trust in authorities are high. The role of health authorities in shepherding the population towards health goals is one of the elements in this discussion. Moreover, the paper will discuss issues of risk and mammography screening as surveillance, as well as normalization and individualization for women in the Norwegian context for breast cancer screening.

Using the same sperm donor for siblings: What it means to parents

Somers, Sara; Ravelingien, A; Provoost, V; Raes, I et al.

Sara.Somers@UGent.be

Study question: How do (prospective) parents perceive and experience the importance of a genetic link between siblings born after fertility treatment with donor sperm?

Summary answer: The use of the same sperm donor for subsequent conceptions appeared quasi univocal and was accompanied by uncertainty about the same donor being available over time. Feelings of luck or relief were mentioned by parents whose children were genetic siblings.

What is already known? Several authors have noted an interesting paradox: while gamete donation allows for detachment of social parenthood from biological relatedness, it is also becoming the area in which biological notions of kinship are reaffirmed. There is an increasing demand for the right to know one's gamete donor; donor offspring are also seeking genetic half siblings through online registries. It remains fairly uncharted territory how parents negotiate the importance of a genetic link between their donor-conceived children.

Methodology: In this study, we included 35 lesbian and heterosexual couples. The in-depth semi-structured couple interviews were performed between October 2012 and October 2013. Data were analysed through step-by-step inductive thematic analysis. A continuous auditing process by the co-authors resulted in themes that were grounded in the data.

The participants were recruited at the Department of Reproductive Medicine of a University Hospital. Twenty couples had a child conceived after a fertility treatment with anonymous donor sperm and 15 were in treatment at the time of data collection. The study was approved by the appropriate Ethics Committee.

Results: We distinguished between families with siblings from the same donor, siblings from a different donor, and siblings with a different biological mother (in lesbian couples). Overall, the couples showed a clear preference to use the same sperm donor for their children. In describing the reasons for this preference, common assumptions were that the genetic link between the children generated better sibling relations, and that (visible) resemblances between the siblings would facilitate social acknowledgement of their family construct. Uncertainty about the availability of the same donor over time seeped through in their stories. For some lesbian couples who decided that both partners should carry a child, the genetic link between mother and child was perceived as more important than a full genetic link between the siblings.

Limitations: This qualitative study aimed at a better understanding of the participants' experiences of and importance attached to the genetic link between their offspring and does not intend to produce generalizable results. Only recipients of anonymous donor sperm were included.

Implications of the findings: These results suggest that, even when the non-biological parent is acknowledged in his role within the family, there is a tendency to favor full genetic

bonds where possible. Full siblings are considered ‘real’, ‘unambiguous’ kin connections. The findings also have possible implications for the clinic: the opportunity to use the same donor for subsequent conceptions seems important for (prospective) parents and should ideally be discussed before the start of the treatment.

Funding: The project is funded by the Special Research Fund of Ghent University. There are no competing interests.

Public health approaches to violent crime

Specker, Jona

j.specker@erasmusmc.nl

Criminal justice and health care traditionally have been separate domains, both formally (division of responsibilities, organizationally) and informally (different evaluative, ethical frameworks). Criminal justice approaches typically emphasize retribution, deterrence, and protection of society. Health care approaches tend to place the interests of the patient central, and emphasize her right to treatment and other forms of support.

These two approaches are characteristically at odds with each other. Whether an offender is judged “mad” or “bad” by a court (or court experts) may have far-reaching consequences in terms of which correcting interventions that are deemed appropriate. A strong focus on safety may clash with a strong focus on care, and bringing both elements together has proven difficult.

Lately, this distinction between judicial and medical approaches has come up in relation to suggestions to take a *health* approach to violent crime. Following our increasing understanding of biological (neurological, genetic) underpinnings of aggression, proposals are being made for the so-called *moral enhancement* of (potential) violent offenders.

In this presentation, I want to ask whether we have reasons to reconsider the division between penal thinking in the criminal justice domain and curative thinking in the health domain. For example, should health care professionals screen for a higher risk of violent behavior in children with behavioral disorders? On the basis of these and other examples, I will discuss advantages and disadvantages of approaching violent crime from a *health* instead of a *criminal justice* lens.

Nosological Values: the Case of Autism

Stempsey, William E

wstempsey@holycross.edu

The case of autism and related disorders illustrates how the values of different interest groups such as clinicians, researchers, patients and concerned members of the public influence nosology. This presentation will focus on changes in different editions of the Diagnostic and Statistical Manual of Mental Disorders and examine how these changes reflect different values embedded in a nosology, their logical relation, and how nosology necessarily favor the purposes of one group or another. The values involved may at first seem to be primarily epistemic in nature, but a wide range of social, political, economic, and ethical values are involved.

The effects of an omnipresence of health checks. Ethical evaluation of health checks should take into account effects that occur due to an omnipresence of health checks, instead of assessing health checks on an individual basis only

Stol, Yrrah

y.stol@erasmusmc.nl

Health checks are offered to, or requested by people without specific medical complaints to test for latent disease, or risk factors for disease. Examples include the commercially offered total body scan, cardiovascular health checks at the GP or ‘traditional’ population-based screening programs. Health checks are ‘on a rise’: more checks on more risk factors and diseases, are offered by more providers to more potential participants. If so many checks are offered, we may speak of an ‘omnipresence’ of health checks.

Health checks provide insight into one’s health status. In case of risk factors or latent disease, preventive action may improve health. However, health checks have disadvantages as well. To evaluate whether or not a health check should be offered, policymakers and public health professionals traditionally make use of laws and regulations, criteria for responsible screening and ethical public health frameworks. The core of this normative framework is that the benefits for participants of a specific check should outweigh the harms of that check. Benefit is usually defined as health improvement; harms include risks for health, autonomy, privacy and equality.

The consensus is the normative framework is still adequate, although not all criteria that were originally developed for governmental screening offers need to be met in commercial screening offers. (Gezondheidsraad 2008, 2015) However, the landscape of health checks not only changed in the sense that screening is offered commercially, but also in the sense that many more checks are offered than before. Where the current normative framework evaluates health checks on an individual basis (assessing whether the benefits for participants of a *specific* check outweigh the harms of that check), it should also take the effects of an omnipresence of health checks into account.

There is abundant evidence in (particular sociological) literature that shows how effects of health checks/health messages accumulate and therefore, should not be considered on their own. For example: health checks appeal to personal responsibility for health. The appeal of a single check may encourage people to take up sports. Very many appeals however could be problematic, for instance resulting in a ‘moral obligation’ to screen and decreased solidarity for those who do not improve upon health where they can.

Omnipresent health checks, therefore, require adjustment to evaluation methods. For otherwise, laws and regulations, existing criteria for responsible screening and ethical public health frameworks risk approving individual health checks while the combined effect of these individual checks does more harm than good.

In this presentation, I will discuss the effects of omnipresent health checks and suggest ways to incorporate these effects into criteria for responsible screening and ethical public health frameworks.

The medicalised good death

Streeck, Nina

nina.streeck@uzh.ch

My presentation aims at disambiguating the concept of the good death and at arguing how today’s ideal of the good death leads to a new medicalisation of dying. Throughout history, people have tried to define what constitutes a good death. I propose that today’s ideal of the

good death involves being able to decide on one's own what actions to take at the end of life, hence, to act autonomously. However, not only autonomy attributes to the concept of the good death, but also authenticity.

In modernity, authenticity became a strong ethical ideal so that Charles Taylor even speaks of an „age of authenticity“ that replaced the „age of autonomy“. In a preliminary sense, authenticity can be described as having one's decisions and actions express one's personality. Thus, authenticity introduces a second aspect beyond leading one's life according to one's self-determined goals as a person's reasons and motives should be an expression of who one truly is and of whom he understands himself to be. Being a strong ideal, authenticity as well orientates today's handling of death and is aspired at one's end of life. Hence, to die one's very own death, i.e. a death that expresses one's personality, characterises good dying.

For palliative care (PC), I suggest, this ideal of the good death is a leitmotif. Therefore, PC orientates itself towards enabling the patient to express her personality at the end of life, i.e. towards authenticity, by trying to meet her wishes and needs. As those comprise all aspects of life PC not only treats her physical symptoms but also her psychosocial and spiritual problems. However, I argue, there is a downside of the orientation towards authenticity. It could lead to the expectation that the patient *must* frame her truly own wishes and needs and create her very own project of dying. Being authentic, then, becomes a demand on the patient that could ask too much of her.

In aiming at helping provide a good death by offering psychosocial and spiritual support at the end of life PC takes into account issues that sharply contrast with the medical domain. That PC introduces medical standards and outcome measures to formerly non-medical fields can be interpreted as a new medicalisation of dying. To conclude, in trying to provide a good death PC medicalises dying.

Medicalization versus own responsibility – A quantitative content analysis of health news

Stroobant, Joyce; De Dobbelaar, Rebeca; Van Leuven, Sarah et al.

Joyce.Stroobant@UGent.be

This paper sets out to analyse to what extent health news is framed in terms of two opposing perspectives by means of a comprehensive content analysis of Flemish media output. On the one hand, a ‘medicalization’ perspective may be adopted in which a (non-) medical problem is defined in medical terms and, more importantly, in which the proposed solution involves some medical treatment, e.g. insulin injections to treat diabetes. On the other hand, journalists can stress the individual's ‘own responsibility’ in maintaining and regaining good health, thus leaving aside medical advice in favour of suggested solutions involving a change in the individual's dietary pattern or physical activity habits, e.g. healthy diet and exercise to treat diabetes (Conrad & Leiter, 2004).

Because of the omnipresence and centrality of news media in our current society, framing health news more in terms of one perspective or the other can have an important impact on health decisions people make on a daily basis (Hallin & Briggs, 2015). Patients do no longer rely solely on their general practitioner for health information. Instead, relations within the medical field have evolved from linear doctor-patient-relations towards a complex network involving many different stakeholders who communicate about health issues, including pharmaceutical companies, patient organizations or health insurance companies (Busfield, 2010). This evolution of the medical field undoubtedly has an impact on the media landscape, since the media are an excellent means for these stakeholders to communicate their message to a wide audience (Williams *et al.*, 2009). Therefore, besides focussing on the

‘medicalization’ versus ‘own responsibility’ opposition, we will also zoom in on journalists’ use of sources. We surmise that journalists’ sourcing practices may have an influence on the construction of health issues; either in terms of ‘medicalization’ or ‘own responsibility’. Thus, we will also examine whether frequent use of source material from, for example, pharmaceutical companies results in a dominant ‘medicalization’ perspective.

Of course, many attempts to study health news have already been undertaken, but these are either single-topic studies (e.g. Hellyer & Haddock-Fraser, 2011) or broad analyses of health news of only one or two (mainly print) media brands (e.g. Robinson et al., 2013). What makes this study unique is the fact that, for the first time, online news sites (e.g. www.gezondheid.be, www.gezondheidheidenwetenschap.be), current affairs programs on radio and television (e.g. Het Journaal, Koppen, Ook getest op mensen, Telefacts, Het Nieuws, Straffe verhalen), newspapers (e.g. Het Laatste Nieuws, De Standaard, Metro) and magazines (e.g. Dag Allemaal, Knack) will be combined in one large-scale media monitoring for a period of one month (February 2015). With this content analysis we are thus aiming to map which perspective (‘medicalization’ versus ‘own responsibility’) is dominant, which health issues receive coverage and how this possibly interacts with journalists’ sourcing practices. This will allow us to evaluate the extent to which media content reflects patterns of medicalization and how this interacts with the health issues presented and the sources used by journalists, thus bringing together the fields of sociology and journalism studies.

References:

- Busfield, J. (2010). ‘A pill for every ill’: Explaining the expansion in medicine use. *Social Science & Medicine*, 70(6): 934-941.
- Conrad, P. & Leiter, V. (2004) Medicalization, Markets and Consumers. *Journal of health and social behaviour*. 45:158-176.
- Hallin, D.C. & Briggs, C.L. (2015) Transcending the medical/media opposition in research on news coverage of health and medicine. *Media, Culture & Society*. 37(1):85-100.
- Hellyer, N.E. & Haddock-Fraser, J. (2011) Reporting diet-related health issues through newspapers: portrayal of cardiovascular disease and Type 2 diabetes. *Health education research*. 26(1):13-25.
- Robinson, A., Coutinho, A., Bryden A. & McKee, M. (2013) Analysis of health stories in daily newspapers in the UK. *Public health*. 127:39-45.
- Williams, S.J., Seale, C., Boden, S., Lowe, P. & Steinberg, D.L. (2009) Waking up to Sleepiness: Modafinil, the Media and the Pharmaceuticalisation of Everyday/night Life, pp. 25-40 in S.J. Williams, J. Gabe & P. Davis (eds.), *Pharmaceuticals and Society: Critical Discourses and Debates*. Malden: Wiley-Blackwell.

Medicalization of HIV cure: philosophical and ethical issues

Rennie, Stuart

stuart_rennie@med.unc.edu

HIV was at first a terrifyingly untreatable disease, which then gradually became treatable with the development of antiretroviral therapy. Although antiretroviral therapy was a remarkable achievement, it still has its shortcomings: patients sometimes have significant side-effects to the drugs, the long-term effects of being HIV positive (even if virally suppressed) are unfavorable, and patients complain of being on continuous therapy (‘treatment fatigue’). Recent clinical developments such as the Mississippi child, the Berlin Patient and the Visconti cohort have indicated that HIV is not only treatable, but potentially curable. However, much of the talk currently surrounding HIV cure has been strongly medicalized, i.e. what a cure consists in is the interaction of certain biomedical interventions

and the virus. The process of medicalisation is reflected in proposed definitions of cure: (1) sterilizing cure, meaning the complete eradication of HIV from the human body, and (2) functional cure, meaning the successful suppression of HIV to an extent that antiretroviral treatment is no longer needed. In this talk, we discuss some of the key advantages and pitfalls of medicalizing HIV cure. On the one hand, speaking of a medical cure and focusing on internal, physical states of HIV infected individuals -- often using military metaphors where the enemy virus is to be attacked and conquered -- may help galvanize attention and resources for HIV cure research. On the other hand, medicalizing HIV cure tends to neglect the psychological and social dimensions of what being cured of HIV might mean for those who have been infected and whose identity has at least been partly shaped by their HIV status. We will discuss what a broader, socialized conception of HIV cure would look like -- including its relationship with associated conceptions such as 'healing' -- and defend the broader conception from an ethical standpoint as what normatively ought to play a larger role in discussions about HIV cure research.

Uncovering medicalization bias in developing a measure of preventive misconception

Sugarman, Jeremy; Seils, Damon; Weinfurt, Kevin

jsugarman@jhu.edu

The preventive misconception involves research participants' false beliefs about a prevention trial, including beliefs that the interventions being tested will certainly be effective. Having a preventive misconception suggests the possibility of a problem with informed consent and may contribute to behavioral changes that could put the research participant and others at risk. Thus, harboring a preventive misconception could be problematic in any prevention trial. However, it may be especially problematic in HIV prevention trials, in which a change in risk behaviors could increase the likelihood of becoming infected. Although mounting evidence suggests that the preventive misconception exists in HIV prevention research, assessing it has not been standardized. We developed and refined a measure of the preventive misconception using qualitative interviews with HIV prevention trial participants. Two main problems emerged during initial interviews. First, the phrase "reduce your risk," used to elicit beliefs about risk reduction from the use of study medications, was interpreted as relating to a reduction of risky behaviors. Second, the phrase "participating in this study," intended to elicit beliefs about trial group assignment, was interpreted as relating to personal behavior changes associated with study participation. That is, the original instrument draft had an inherent medicalization bias in assuming that 'risk' related to the use of the experimental agent to reduce the chance of infection was most salient to participants, yet participants privileged the behavioral changes that accompany participation in research. Similarly, whereas the original draft assumed study arm assignment would be of considerable relevance to participants, this was trumped by broader considerations related to participation in the study. Additional interviews using a revised measure suggest that it is valid. These findings underscore the importance of using cognitive testing to refine surveys of this nature so as to uncover items that may be problematic due to medicalization bias or other considerations. Having a valid measure for the preventive misconception will facilitate further empirical research regarding this concept and its potential relationships to the risks faced by participants and for informed consent. Such information will also be useful in refining related conceptual work on the preventive misconception.

What kind of creature is ADHD? Personalities and pathologies in the neuropsychiatric era

Svenaesus, Fredrik

fredrik.svenaesus@sh.se

Psychiatric diagnoses such as anxiety disorders, depressive disorders, bipolar disorders, personality disorders, and, not least, neurodevelopmental disorders have increased in prevalence quite significantly during the last 35 years. The increases in question are often understood to be, at least partly, cases of medicalization of psychic suffering in which problems and shortcomings that were previously not considered from a medical angle are now given medical explanations and suggested solutions. Medicalization is a pejorative term, which means that a claim that the human problems and shortcomings in question are not really medical in nature tends to follow with the very use of the word. The question, however, is how such claims could ever be proven or disproven. In psychiatry, as well as in public debates, we often find claims that disorders, like ADHD, are over- or under-diagnosed in the population. The claim is often made that they are both over- and under-diagnosed at the same time, since some persons who visit health care get the diagnosis without really suffering from the disorder, whereas other persons suffer from the disorder without ever seeking medical help for their problems. However, every claim that a psychiatric disorder is over- or under-diagnosed rests on the assumption that the identification of clusters of symptoms that make out the disorders, in manuals such as DSM-5, manage to separate the ill from the healthy. Such claims seem exaggerated in absence of not only an established definition of mental disorder as such, but also an understanding of the dysfunctions of the brain and body that would be responsible for the disorders in question. What I want to stress in this talk, with the example of ADHD, is that the most important question may not be whether psychiatric diagnoses really equal pathologies – they probably do not, but the answer will always be dependent upon how we define and understand mental disorder. The most important question is why we are so keen on finding medical explanations for the experiences and behaviours targeted by way of psychiatric diagnoses. My tentative answer to this question, that I will expand upon in the talk, is that the explanatory patterns traditionally used to cope with psychic suffering and problems – religion, politics, psychoanalysis, etc. – currently do not work well as sources of meaning and understanding in Western societies. Religious, political and psychoanalytical explanations and cures for human suffering and problems have been delegitimized and replaced by the only institution that we currently trust: science. As a result of this process, only medical explanations and solutions make human suffering and problems real and this is terribly important for the persons involved. Psychiatric diagnoses provide (quasi) scientific patterns that reify and provide legitimacy for all parties involved: doctors, patients, politicians and, perhaps, philosophers, too.

Revisiting a. buchanan's criticism of the extreme connectedness argument

Sýkora, Peter

petersykora111@gmail.com

In February 2015 the U.K.'s Parliament voted to approve changes to the law allowing fertility clinics to carry out mitochondrial replacements. From bioethical perspective it is a historical step since both approved techniques of a mitochondrial replacement, the maternal spindle transfer and the pro-nuclear transfer, can be classified as a inheritable genetic modification (IGM). Until recently, IGM in humans have been considered to be an ethical demarcation line not to be crossed. One of the most influential arguments against the use of IGM interventions

in humans (germ-line gene therapy or genetic enhancement) is that they are almost certainly at risk to destroy a human genetic nature. According to this argument, human nature is a highly complex whole, a delicately balanced web of gene interactions, too fragile for any kind of IGM interventions.

The aim of this paper is to revisit A. Buchanan's criticism (Buchanan 2011) of the Extreme Connectedness Argument used in enhancement debate from a perspective of recent empirical discoveries in human genetics. According to findings of ENCODE Research Consortium a human genome is not „a collection of independent genes but rather a complex network in which genes, along with regulatory elements and other types of DNA sequences that do not code for proteins, interact in overlapping ways not yet fully understood.“ Also some recent findings in mitochondrial DNA seems to challenge a traditional view on mitochondria as only cellular „powerhouse of the cell“. In this context, I argue that the approval of mitochondrial replacement techniques was premature. First, because more information about interactions between mitochondrial and nuclear DNA is needed. Second, more animal experiments with non-human primates should be done before first human clinical experiments with the maternal spindle transfer and the pro-nuclear transfer techniques start.

Synthetic biology, medicalisation and the beast machine

Takala, Tuija

tuija.takala@helsinki.fi

Synthetic biology promises us new ways of manipulating genes, cells and proteins. Its potential applications are almost endless and range from, say, better building materials and biofuels to designer babies and for-a-purpose built completely new organisms. Many of the ethical issues raised by synthetic biology bear close resemblance to those discussed in connection with genetics. And until life is actually 'created from scratch', the issues will remain, I would argue, fairly similar.

However, in applying the principles of engineering to biological organisms, such as humans, synthetic biology comes to represent a new approach to life in general and human life in particular. Humans are viewed like machines with more or less faulty building blocks and software. While genetics took us one step further towards medicalisation, where an increasing number of human problems are seen as appropriate targets for medical interventions, synthetic biology seems to take us even beyond that. The solution is no longer to prevent and to treat, but to make sure that the building blocks are the best possible ones and that the software runs flawlessly. With synthetic biology, we could talk about the mechanisation of human life.

In my presentation I will discuss synthetic biology as a representative case of medicalisation and mechanisation. Both of these have to do with justice, power and control, but there is also the very concept of humanity being challenged. In terms of our concept of ourselves as humans and the ways we try to tackle the problems we face, giving in to a mechanistic view of life has several serious shortcomings.

Who can access my medical information? – A new privacy paradigm for health data

Tamin, Jacques

drjsftamin@hotmail.com

It can be argued that if our lives are increasingly medicalised, then it is possible that more of our information has become “medical” or “health” information. In the United Kingdom (UK),

health information projects such as the NHS medical records database have been controversial³¹, amid fears of privacy being breached. It will be argued that current laws in the UK do not protect privacy of health information sufficiently.

Privacy has been defined as “a state of separateness from others” and the right to privacy has traditionally been described as “the right to be alone”. For the purposes of this paper, a more useful conception of privacy is to see it as “the condition of not having undocumented personal information about oneself known by others”³². A development of the right to privacy then “involves treating the *control* of information as inherent in privacy”³³. The academic debate on the meaning of privacy has been mirrored in European and UK Court judgments in the last ten years, and the “control of one’s information” has emerged as an important principle. However, Tavani has criticised this “control theory” as “confus(ing) privacy with autonomy”³⁴, and proposed his “Restricted Access/ Limited Control” (RALC) theory instead. The aim of this paper is to propose a different health privacy paradigm, based on Tavani’s RALC approach. Its application will be described in the context of occupational health information.

Health, empowerment and capabilities

Tengland, Per-Anders

per-anders.tengland@mah.se

The discussion about theories of health has recently had an important new input, namely, through the work of Sridhar Venkatapuram. His strategy is to combine Lennart Nordenfelt’s holistic theory of health with Martha Nussbaum’s version of the capabilities approach. Thus, he places himself firmly in the holistic tradition. The theory of health suggested is, however, not the endpoint of his endeavour; his primary purpose is to provide us with a theory of health justice. The first aim of the present paper is to discuss and evaluate Venkatapuram’s theory of health and its use in a theory of health justice. For this purpose, I will first compare Venkatapuram’s theory with a few others, starting with that of Nordenfelt and continuing with an alternative, two-dimensional, theory of health. This will show some of its weaknesses and, at the same time, clarify the relation of (the alternative theory of) health to the capabilities approach. Secondly, the aim is to account for health in relation to social and global justice. The attainment of health, it is argued, is primarily an instrumental goal, i.e., one that helps the individual reach other goals. As such health cannot in itself be the primary “currency” in (or goal for) a theory of justice. What then is? Capabilities is one answer, empowerment another, and quality of life is a third one. The second half of the paper discusses the relation between these answers, arguing that empowerment should be the explicit goal in a theory of justice (even though it is also instrumental), since it is defined in terms of quality of life. The difference in relation to the capabilities approach is small, however, as the theories are to a large extent overlapping. Health justice is important, as Venkatapuram claims, so the paper ends by explaining why health, even though it is not primarily a final goal for justice, is still important for a theory of justice.

³¹ The Telegraph, NHS medical records database halted amid concerns, <http://www.telegraph.co.uk/health/nhs/10647031/NHS-medical-records-database-halted-amid-concerns.html>

³² W. Parent, *A New Definition of Privacy for the Law*, Law and Philosophy, 1983, 2, 3, 305-338, at 306.

³³ J.V. McHale, *Medical Confidentiality and Legal Privilege*, Routledge, London, 1993, 55.

³⁴ H.T. Tavani, *Philosophical Theories of Privacy: Implications for an Adequate On-line Privacy Policy*, Metaphilosophy LLC and Blackwell Publishing Ltd, 2007, 38, 1, 1-22, at 8.

The pharmaceuticalization of public health and ethics: The case of ebola

Thompson, Alison

A.thompson@utoronto.ca

In this paper I propose to explore the notion that discourses can become subject to a process of pharmaceuticalization. I will present the findings of a critical discourse analysis of the academic bioethics and public health ethics literature on ethical issues in the ongoing outbreak of ebola virus disease (EVD) in Africa. EVD provides a fertile case study of how academic discourses around “what we ought to do” in response to public health crises can become dominated by normative analyses that centre on pharmaceuticals.

As a relatively new field of study, public health ethics has yet to consider the normative implications of what Beihl calls the “pharmaceuticalization of public health.”³⁵ While the inadequacy of traditional bioethical analyses of EVD has been described by Dawson³⁶, I will argue that the dominance of ethical discourses pertaining to the proper use, study and distribution of pharmaceuticals in this context is highly problematic. Using insights from critical discourse analysis theory³⁷ and a public health ethics theoretical framework that draws on the work of Powers and Faden³⁸ I hope to show that the dominance of pharmaceuticalized discourses around infectious diseases like EVD constrain the production of knowledge, dissent and difference. In the context of the current EVD outbreak, this leads to the exclusion of or diminishment of discourses that address the global justice aspects of EVD and how we might imagine a response that is different than the one that nations have provided to date.

The implications for future infectious disease outbreaks, particularly those of international significance, will be explored. In addition, the implications for bioethics and public health ethics will also be probed.

The medicalization of lifestyle: Demonizing persons and maligning virtues

Tschaeppe, Mark

mdtschaepe@pvamu.edu

One of the most frequently used causal concepts in contemporary medicine and public health is that of lifestyle, which has become a convenient category in which persons may be grouped as potentially or actually ill or healthy. Although the intent of such classifications is primarily for diagnostic efficiency rather than moral judgment, I argue that the medicalization of lifestyle as a category of illness and health smuggles underlying normative judgments into diagnostic processes that obfuscate problem-solving capabilities of both medical staff and those persons diagnosed. The underlying normative judgments smuggled into the diagnostic process are based, *inter alia*, upon a maligned concept of virtues that has extended beyond specific habits to overarching normative classifications of persons placed within risk groups. I suggest that the medical category of lifestyle, although convenient to the diagnostic process, carries with it too much risk compared to its benefits. To elucidate this suggestion, I use two

³⁵ Beihl, J. in *Global Pharmaceuticals: Ethics, Markets, Practices* (eds. Petryna, A., Lakoff, A. & Kleinman, A.) 206–239 (Duke University Press, 2006).

³⁶ Dawson, A. J. Ebola: what it tells us about medical ethics. *J. Med. Ethics* **41**, 107–110 (2015).

³⁷ Wodak, R. & Meyer, M. *Methods for Critical Discourse Analysis*. (SAGE, 2009). at <https://books-google-ca.myaccess.library.utoronto.ca/books/about/Methods_for_Critical_Discourse_Analysis.html?id=tNRWsrPiNQoC>

³⁸ Powers, M. & Faden, R. *Social Justice: The Moral Foundations of Public Health and Health Policy*. (Oxford University Press, USA, 2008).

recent cases of the medicalization of lifestyle that have been used as causal contributors to disease: homosexuality and obesity.

The homosexual lifestyle was the first category of risk indicated following the index case of what would come to be known as AIDS. Historical analysis of the use of the category of homosexual lifestyle in the initial discovery and diagnosis of the disease provides a telling example of the ethical dangers of using lifestyle as a medical category to replace, even for a brief moment in time, that of habit.

The category of obesity has also been tethered to lifestyle, which has surreptitiously devalued and demonized those who have been placed within that medical category. Just as AIDS had initially been explained by lifestyle over habits, obesity has become explained through an overarching trajectory of lifestyle instead of particular habits within that lifestyle. By diagnosing lifestyle over particular habits, normative judgment has been made upon those classified as occupying that specific lifestyle.

Through the medicalization of homosexuality and obesity as etiological lifestyles, a dangerous conception of virtue has been presumed that may stifle prevention and treatment of disease. Removing all normative judgment from medicine is likely impossible, but the medicalization of lifestyle has proved ethically precarious when used as an etiological concept.

Parents ought not to have the power to consent to elective genitoplasty on their newborn (intersex) child

Uí Chonnachtaigh, Sorcha

s.ui.chonnachtaigh@keele.ac.uk

This paper, part of a broader project examining the social regulation of sex, gender and sexuality will focus on the role of parents in decisions to have non-medical genital surgery performed on their intersex child. In particular, the problem of parental distress will be analysed. Parental distress at the atypical genitalia of their child is most often cited by medical professionals as sufficient reason for performing irreversible “genital-normalising” surgery (GNS) on newborn and infant children, even when those professionals would generally advocate deferring surgery (Joint ESPE/LWPES CAH Working Group 2002; Rangecroft 2003; Hughes et al 2006). While performing such surgeries at a young age allows for the best possible physical recovery, deferring surgery till 16-18 years does not significantly reduce physical recovery and there are many ethical problems.

Elective genital surgery at a very young age has physical and psychological risks. The decision to have the surgery performed involves certain dangerous assumptions about gender, sex and sexuality (Fausto-Sterling 2000). Firstly, there is an assumption that a child’s future gender identity will ‘match’ the sex assigned through surgery. Secondly is the assumption that heteronormative penetrative sex is the only satisfactory way in which a healthy sex life can be achieved. Thirdly, there is the obviously problematic assumption that certain genitals (of a certain size) will correlate to the child identifying as a certain sex - a sort of genital determinism. These presumptions cannot be made with regard to any child but it is particularly risky to make them with an intersex child (they can be, and are, shown to be incorrect). Proceeding with NGS on these presumptions can result in significant irreversible harms for the individual child while also reinforcing common binary conceptions of sex and gender that have a harmful impact on others who defy them.

Parents traditionally have a significant amount of discretion when it comes to decision-making on behalf of their young children regarding their bodies, even for interventions that are not medically necessary (from ear-piercing to ear-pinning, male circumcision and

birthmark removal). However, parents are not constrained in the same way as the State is (i.e. child's best interests) and this can be problematic (Hannan & Vernon 2008).

It will be argued in this paper that parents ought not to have the authority to consent to GNS for their newborn child but that the best way to end such surgeries would be a blanket ban on GNS for newborns and young children by the professional organisations of the relevant medical professionals. If the relevant professional bodies continue to resist such an absolute prohibition, then criminalisation of GNS (as has been done for similar practices like female genital mutilation) may be the only alternative.

The recently adopted council of Europe convention against trafficking in human organs: An analysis of its content and crucial importance

Van Assche, Kristof

Kristof.VanAssche@ugent.be

Prompted by a severe shortage of kidneys for transplantation, desperate patients suffering from kidney disease may feel tempted to resort to illicit means in order to obtain an organ. The practice of purchasing or illicitly obtaining kidneys has been reported since the late 1980s. In response, prohibitions to curb this practice became enshrined in numerous international guidelines and legal instruments enacted by a variety of intergovernmental and medical organisations. However, progress has long been impeded by the lack of a comprehensive and binding international criminal law instrument. This need was finally addressed by the adoption of the Council of Europe *Convention against Trafficking in Human Organs*, which opened for signature on 25 March 2015.

This presentation will focus on the crucial importance of the *Convention against Trafficking in Human Organs* as the first international binding legal instrument that addresses all types of illicit transplant-related activities and explicitly requires their criminalisation. This presentation will consist of four parts. First, a brief introduction will be given of the background to the drafting and adoption of the *Convention*. Second, the distinct activities that constitute "trafficking in human organs" will be analysed, with due attention paid to its central concept of "illicit removal of organs". Third, the added value of the *Convention* will be discussed as compared to other important international guidelines and legal instruments in the field of transplantation, most notably the World Health Organization's *Guiding Principles on Human Cell, Tissue, and Organ Transplantation*, the World Medical Association's *Statement on Human Organ Donation and Transplantation* and the Council of Europe *Convention on Human Rights and Biomedicine* and its *Additional Protocol concerning Transplantation*. Fourth, the complementarity will be examined of the *Convention against Trafficking in Human Organs* and the binding international legal instruments addressing trafficking in human beings for the purpose of organ removal, namely the United Nations *Protocol to Prevent, Suppress and Punish Trafficking in Persons*, the Council of Europe *Convention on Action against Trafficking in Human Beings* and EU Directive 2011/36/EU. The presentation will conclude with an assessment of the expected practical impact of the *Convention against Trafficking in Human Organs* on ratifying States and beyond.

Pharmaceuticals as solution for health problems: A stakeholder perspective

Van den Bogaert, Sarah; Declercq, Jana; Van Leuven, Sarah et al.

Sarah.VandenBogaert@UGent.be

This study is situated within current discussions of ‘medicalization’ (Conrad, 2005, 2007) and ‘pharmaceuticalization’ (Williams, Martin & Gabe, 2011). Relations within the medical field have evolved from linear doctor-patient-relations towards a complex network involving many different stakeholders. The field of health and health care has evolved into a medical market in which health is increasingly seen as a commodity; patients are perceived as consumers and medicines are turning into consumer goods (Busfield, 2006). This evolution has broadened the debate about medicalization and has led to the emergence of the concept of ‘pharmaceuticalization’, which implies that social, behavioral or physical conditions require a treatment with pharmaceuticals (Abraham, 2010; Williams, Martin & Gabe, 2011). In the medical market, one important new ‘driver’ (Conrad, 2005, 2007) of the ‘pharmaceuticalization of society’ is the pharmaceutical industry (Williams, Martin & Gabe, 2011), which increasingly targets the public, but more research is needed to fully understand which ‘drivers’ or stakeholders contribute to this development. Therefore, using a stakeholder mapping technique, this study aims first to identify the stakeholders that are involved in the production and/or distribution of information about pharmaceuticals in the Belgian medical market. Second, by means of in-depth interviews, we want to gain more insight in their discourses on pharmaceuticals as a means to examine to what extent they act as ‘drivers’ of the pharmaceuticalization of the Belgian health landscape. Our stakeholder mapping revealed eight relevant stakeholder categories: the media, the pharmaceutical industry, government institutions, health insurance companies, patient organizations, consumer organizations, academic medical experts and organizations of health professionals. To study the discourses of these stakeholders, a minimum of 32 semi-structured interviews (four per stakeholder category) will be conducted from March to June 2015, with key persons at management level (CEO and PR/communication) within the selected organizations. We will ask these different stakeholders about their definitions of health and illness, and their views on possible causes and solutions for health and illness. We expect that government institutions, the pharmaceutical industry, the media and organizations of health professionals are important drivers of pharmaceuticalization (Williams, Martin & Gabe, 2011). By contrast, we think that health insurance companies, patient organizations, consumer organizations and academic medical experts will focus more on other solutions than pharmaceuticals, such as weight loss, dietary changes or physical exercise.

References:

- Abraham, J. (2010). Pharmaceuticalization of society in context: theoretical, empirical and health dimensions. *Sociology*, 44(4), 603-622.
- Busfield, J. (2010). ‘A pill for every ill’: Explaining the expansion in medicine use. *Social Science & Medicine*, 70(6), 934-941.
- Conrad, P. (2005). The shifting engines of medicalization. *Journal of health and social behavior*, 46(1), 3-14.
- Conrad, P. (2007). *The medicalization of society: On the transformation of human conditions into treatable disorders*. Baltimore: The John Hopkins University Press.
- Williams, S. J., Martin, P., & Gabe, J. (2011). The pharmaceuticalisation of society? A framework for analysis. *Sociology of Health & Illness*, 33(5), 710-725.

Pediatric clinical trials: The ethics of burden without consent

Van Hoof, Wannes

wannes.vanhoof@ugent.be

There is an urgent need for safe pediatric drugs. More than half of the drugs that are prescribed for children are used off-label and many childhood diseases are insufficiently researched for potential drug treatments. The dominant discourse about pediatric clinical trials was that testing children is ethically problematic, but currently the consensus is that not testing is even less acceptable. The result is that pediatric clinical trials are accepted, but strict rules regarding informed consent, recruitment, minimal burden and direct benefit must be followed. The ethical discussion has mainly focused on informed consent in pediatric clinical trials, even though such trials present the perfect case to indicate that autonomy is not always the most important principle in medical ethics. The core issue in pediatric clinical trials is how to compare the burden for the child with the potential benefits given that children are a vulnerable group that cannot give informed consent.

‘Minimal burden’ and ‘direct benefit’ are both very general concepts that require specification. A general difficulty with both concepts is uncertainty: very young children may not be able to express excess burden or pain and the outcome of a trial is unsure by definition. The standards of minimal burden and direct benefit should not always compare to either daily life or the burden of non-treatment or off-label treatment, but to the best available alternative. Strategies to minimize burden include minimizing the number of participants, limiting visits to the clinic and taking as little samples as possible. It has been argued that direct benefit should be interpreted on an individual level, but this would be impossible in practice and diminish the quality of many trials, for example because of implications for randomization. One way to ensure direct benefit is to ensure continued access to the tested drug if the trial is successful. In practice, the concepts are interpreted as a sliding scale where expected burdens must be proportional to the projected benefits. An inherent problem for this proportionality is that many strategies to minimize burden potentially diminish the quality of the data, which impacts the benefit of the trial.

Because young children cannot give informed consent and are often unable to clearly communicate their preferences, the investigators have an increased responsibility to balance beneficence and non-maleficence in pediatric clinical trials.

How do we relate to each other? Children’s, parents’ and donors’ perspectives in sister-to-sister oocyte donation families

Van Parys, Hanna; Provoost, V; Wyverkens, E et al.

Hanna.VanParys@ugent.be

Although sister-to-sister oocyte donation has been practiced for at least 15 years in several countries, little is known about family relations within these families. Literature points at strong and stable sister relations. However, relations between donor and child and between parents and child are relatively underexplored. The current study aimed to offer an in-depth understanding of multiple family relations within these family constellations, based on the perspectives of both parents, children and the donor. The research question was: ‘How do family members experience family relations in sister-to-sister oocyte donation families?’

As part of a bio-ethical qualitative research project on family members’ perspectives on social and genetic parenthood, semi-structured interviews were conducted with heterosexual couples, their oocyte donors and one of their children. Participants were recruited via the Department of Reproductive Medicine of the Ghent University Hospital. Couples eligible for

the study were contacted by their counsellor seven to ten years post treatment. Two couples, one mother, three oocyte donors and three children were interviewed separately. Interviews were analysed using Interpretative Phenomenological Analysis, followed by an analysis within families and a comparison across families. The project is funded by the Special Research Fund of Ghent University. Approval by the appropriate Ethics Committee has been obtained.

Family members stressed that their relationships have always been strong, independently of the oocyte donation. What prevailed was thankfulness towards the donor, and a sense of being able to contribute in the donors themselves. Parents and donors put forward that they did not make initial arrangements apart from the decision to disclose to the child, which in all cases was left to the parents. While overall the role of the mother was clearly distinguished from the role of the aunt/godmother, in two families the donor reported increased feelings of responsibility or even primal mother feelings right after the birth of the child. In these families, being a godmother seemed to have a symbolic function, capturing the increased responsibility that was felt towards the donor child.

The current study provides a deeper understanding of family relations underlying and stemming from sister-to-sister oocyte donation. In counselling, the necessity of long-term arrangements regarding the rights and responsibilities of the different parties, is often presupposed. The participants in our study however, pictured the donation as a spontaneous undertaking, based on mutual trust. At the same time, counsellors can play a role in exploring the different meanings of genetic links together with all parties.

Ethical boundaries of palliative sedation

Vandersloten, Goedele; Beyers, Fleur

goedelevandersloten@hotmail.com

Throughout the years, the position (both theoretical and practical) of death in our society is subject to much controversy. Whereas death and dying once were a central part of life, an important event in society, nowadays, death is something we fear, we want to stay away from. It is an event we do not speak of, as if it were contagious. It has been moved to the margin. In line with our tendency to constrain all matters that concern life, death has also become subject to this symptom of modernity. What do we long for? The perfect death on delivery, painless, harmonious and preferably a strictly private issue. On the one hand we postpone any discussion on the subject as long as possible, and on the other we want to be able to have all power over our own death. To orchestrate and stage our death, as if it were a spectacle needed in order to validate the worthiness of our lives. Where does this need to constrain all matters of life come from? Who has the eventual and final say about our lives and our death? Why is death such an ambiguous subject: on the one hand we prefer to avoid it, but on the other hand there is a tendency that draws towards the subject. It is “hot” and sensational, popular culture is filled with references on death and violence.

Death, the end of life, has – due to evolutions in medical science - been medicalised to a great extent. Research shows us that 50% of deaths are preceded by a medical decision that has an influence on the end of life (Vanderheide, A., Deliens, L., Faistt, K. et al., 2003). Palliative sedation and euthanasia are two examples of the six possible medical decisions that can precede the end of life. Palliative sedation is considered to be “normal medical practice” (van Delden, 2007), a form of profound pain and symptom-control that lowers the awareness of the patient to such an extent that one or more refractory symptoms are relieved. Euthanasia is the intentional termination of life at request of the patient himself.

Theoretically, we could say that these two medical actions are different: in their goal, their intention, medication and implication. Both actions are also subject to conditions of care which are designed to make these practices morally and ethically tolerable. In practice however, we see that these rules are simply not applicable to all cases, for reasons that will be further discussed in this paper. We will also address the question to what extent palliative sedation differs from euthanasia, and on which grounds the one will be preferred over the other.

Do we obtain a “worthy” dying process by simply following the rules that the medicalised world has imposed on this process? Can we speak of an autonomous decision when the patient’s awareness is lowered to such an extent that he has no longer the ability to indicate his own final will?

In this paper, we will discuss the ethical aspects and boundaries of palliative sedation. We will base our analysis on case studies derived from daily practice, and theories derived from authors such as Michel Foucault, Giorgio Agamben, Philippe Aries and Ivan Illich.

On the unfortunate misconception about facts and values in health technology assessment and its deplorable consequences

Van der Wilt, Gert Jan

GertJan.vanderWilt@radboudumc.nl

Health Technology Assessment (HTA) is the systematic inquiry into the value of health care technologies when used in specific contexts. From the outset, exploring ethical issues has been recognized as an important element of HTA. In spite of this, ethical analysis has played a marginal role in HTA. Various explanations have been offered for this apparent anomaly. In the present paper, we wish to explore a novel thesis: the rigorous separation of facts and values in HTA has significantly hampered in getting empirical analysis and normative inquiry on an equal footing. The current practice of HTA is dominated by a rigorous distinction between assessment and appraisal. Assessment refers to the collection of facts about a healthcare technology: does it produce any side-effects, is it cost-effective, does it improve the quality of the lives of patients, etc? Appraisal refers to the process where, based on the collected data, a judgment is reached on the overall value of the healthcare technology, taking into account any further considerations that may be considered relevant. Typically, the latter include considerations of equity, solidarity, autonomy, etc. Following the work by the Hungarian philosopher Julius Kovesi (1967), we submit that this practice testifies of a complete misconception of the relation between facts and values. What is wrong with the current approach is that it assumes that a value-neutral description of consequences can be obtained, which may then be explored for its normative acceptability. This is not the case. In fact, it is rather the other way round. Value frameworks are operative at the stage of data collection, defining what is, and what is not, considered relevant. Thus, the results of an HTA may be viewed as a particular collocation of facts, that are considered relevant in view of certain underlying moral and non-moral notions. In Kovesi’s words: evaluation [such as HTA] does not evaluate the world of description, it describes the world of evaluation. If this is correct, it becomes vitally important to explore the moral and non-moral notions that guide the data collection that is constituted by HTA. In the present paper, the implications this might have for the practice of HTA will be explored, using cardiac pacemakers in elderly patients as an example. Ethical inquiry is, then, no longer an ‘end-of-the-day’ reflection on the acceptability of the ‘given’ consequences of adopting a healthcare technology in a particular healthcare system. Rather, it moves to the forefront of HTA, guiding deliberations

on which aspects might be relevant, and for what reason, and how conflicting requirements might be practically resolved.

Which kind of diagnosis in psychiatry?

Vanheule, Stijn

Stijn.Vanheule@UGent.be

In contemporary psychiatry, diagnoses are usually made by means of the Diagnostic and Statistical Manual of Mental Disorders (DSM). Since 2013 the 5th edition of the manual is frequently used: DSM-5. In this paper I discuss how the DSM-5 starts from a biomedical account of mental disorders, while biomedical data supporting this account are largely lacking. Current diagnostic projects like the Research Domain Criteria Project (RDOC) of the NIMH follows a similar logic. I review the natural kinds approach underlying DSM-5 and RDOC, and discuss how, via phenomenology and psychoanalysis, psychopathology can be thought as a domain of 'reflexive kinds'.

The need for an existential phenomenological approach to the wish to die in elderly people: Thoughts about the interface between normality and pathology

Van Wijngaarden, Els; Leget, Carlo; Goossensen, Anne

els.vanwijngaarden@phd.uvh.nl

When elderly people are ideating on manners to end their lives, because they feel life is over and no longer worth living, it is important to understand how they experienced their lives in order to comprehend their thoughts and behaviour and to appropriately align care and support to the needs of these people. In the literature, the wish to die in elderly people is often understood from a medical, psychopathological paradigm, referred to as cognitive impairment, depressive disorder, pathological bereavement, and suicidality. In this paper, we evaluate this dominant paradigm and we plea for an existential phenomenological approach, by using the insights from our empirical-phenomenological research on elderly people with a wish to die.

The medical, psychopathological paradigm has some limitations. Firstly, it might reduce the wish to die to a mental disorder and tend to classify people into nomothetic categories, defined by clusters of symptoms, prevalence, and potential risks. Mental states are never abstractions, but they reveal themselves in the reality of the surrounding world, of objects, and of personal relationships. The focus on objective diagnostics might strengthen a negation of the lived experiences, and consequently a denial of the person's subjective truth. Secondly, this reduction might lead to 'mismatch' and poor alignment of support to the concrete needs and concerns of people. If we want to understand a person's existence, we need a phenomenological understanding which is not primarily cognitive, intellectual and technical but rather pathic, which means situated, relational, embodied and enactive. By underestimating this pathic knowledge, the medical model might fail to sufficiently validate the existential concerns and suffering of these elderly people. Thirdly, this approach medicalizes a social phenomenon before analysing it properly and openly, thus putting medicine in a position of power, without asking whether it is sufficiently equipped to deal with the multifacetedness of the phenomenon. Lastly, this paradigm strongly tends to focus on the wish to die as a private and individual problem, which contains the risk of ignoring the social and cultural embeddedness of this wish.

Without trivializing the need of good diagnostics, the authors argue the need for an (additional) existential approach, with careful attention for the lived experiences of individuals, and their (social and cultural) situatedness. When existential concerns are recognised, elderly people have an opportunity to understand themselves in a way that is not defined as a medical disorder, but as a part of human existence. Taking into account these existential concerns might also help to improve and humanize care and policy for these people.

Medicalization of death syndrome: An Indian philosophical view point

Vaswani, Vina

bioethics@yenepoya.edu.in

Over the years, in India, the definition of death has undergone a sea change from the earlier cessation of circulation, respiration and brain functions to the current focus on brain death and brain stem death. Considering the fact that most developed nations have discarded the brain stem death concept, it is theoretically feasible to have a patient be called 'dead' in one country yet 'living' in another. Technological advancements have blurred what was once traditionally a well-defined, one-moment event. A person once declared dead, can now be kept on ventilator for months to years, raising the question "Is there a single moment of death"? Is it a myth or reality? Can this moment be left to doctors to declare?

Among the Hindu scriptures the Vedas are the most ancient texts. The Upanishads came after and drew inspiration from the Vedas. Whereas the former (descriptive) used poetic and symbolic expressions, the Upanishads (more prescriptive or normative) were more direct in language. The Upanishads exhort man to live a life without pity and court death without pain. Thus one can see that the concept of a 'dignified' death is not foreign to the Indian ethos.

Santhara is a religious ritual of fasting till death, observed in the Jain community of India. A person takes the vow of *sallekhana*, denouncing food, medicine and water when she is ready to quit life. Similar practice is seen in Hindus also where a person denounces food and spends his life in reflection. This is believed to clear the residual karmic debts and prevent the creation of new ones through indulgence. Sallekhana is also believed to facilitate the smooth separation of the infirm, diseased body from the soul, at the time of death.

Even in the present day, the fabric that defines Indian societies is the extended family. Notwithstanding the urban nuclear family structure which forms a minor part of the population, the large majority still function through expanded vertical generations and horizontal relations. At times, even non-family community members are involved in decision-making processes. Thus, even in ordinary life, decisions are taken keeping multiple personalities in the focus. It is not surprising that decisions on end-of-life are family and society-centric rather than patient-centric. To that extent autonomy is not a case of empowering individuals to act in the interest of self.

Yet another unexplored dimension is the divergent value systems in Indian allopathic doctors who are socially rooted in the extended non-individualistic autonomy model but professionally trained in healthcare systems that largely draw from the self-determination model. Hence in end-of-life decision-making situations, the deliberation on prolonging life or withdrawing life-support, may not be a conscious choice of an individual patient but is driven by the economic and social power equations of the family members along with the physician. Although it is their life, very rarely does the patient herself get involved in the discussion. Many doctors practicing modern medicine and not sensitized to religious beliefs tend to consider the request to withdraw treatment as 'not agreeable', as it challenges their notion of beneficence.

This study explores the issue of medicalization of death vis-à-vis the traditional beliefs by interviewing terminally ill persons on the one hand and doctors on the other.

Nano-medicine, expanding the biomedical gaze

Vegter, Mira W

m.vegter@science.ru.nl

Nanotechnology has been referred to as ‘enabling’, making possible new socio-technological developments in various fields. It has also been called a ‘converging science’, as it brings various fields such as molecular biology, biophysics and chemistry closer together. One particular subfield of nanotechnology broadly speaking is nano-medicine. Again, it is both an enabling field (opening up new application in drug delivery and tissue engineering for example) and a converging field (bringing together for instance nanomaterials research and tissue engineering). Cutting-edge developments in nanoscience and molecular biomedicine seem promising for addressing challenges such as degenerative brain diseases, for example research into targeted mitochondrial drug delivery.

In this paper I would like to address the emerging field of nanomedicine and explore the various ethical and philosophical questions it raises. Apart from the potential benefits in terms of medical applications, I would like to develop our sensitivity to broader impacts such as on how we see life, embodiment, technology and human autonomy. Three dimensions of nanomedicine will be highlighted here. First there is the possible consequence of enforcing medicalisation, increased measurability and monitoring may change the way we experience personal health (further extending the biomedical gaze). On the one hand this may lead to empowerment and self-management, but the need for systematic monitoring in combination with new diagnostic tools may lead to medicalisation of individuals who formerly experienced themselves as healthy: thus increasing their dependence on high-tech medicine. In many ways we seem to be overpowering nature, thereby empowering ourselves by fighting what at first seem to be threatening dimensions of nature: biomedicine as a form of liberation and emancipation. But by doing so we become more dependent on modern technology and science-based expertise. Another issue is promise management. Whereas the engineer may see new possibilities for intervention on the horizon, others will rather emphasize the recalcitrance and complexity of human bodies and *their resistance to intervention*. Finally, the increased proximity and almost identity of techne and bios raises a number of issues. On the one hand, technology becomes biomimicry even on the molecular level, increasing the possibilities for embedding new technology in living systems. On the other hand, these living systems are defined in a technical way. Technologies become pervasive, moreover, they enter our bodies and brains, opening up new opportunities for intervention. Science fiction is becoming science, but this new power is quickly becoming uncanny.

Notwithstanding opportunities in terms of diagnosis and treatment in the field of Nanomedicine, it may lead to a situation in which even healthy individuals become early stage patients, and health becomes an outdated category. To get a sense of where the norm is shifting towards we need to look at what is happening in molecular biology. Only when we see how the molecular scale research relates to the clinic we become aware of the possible futures of medicine. There is a possible symbiosis between nature and technology, but the uneasiness that accompanies a hybrid such as nano-medicine should serve as a reasonable touchstone.

Physician assisted suicide and the role of psychiatrists. A new medicalization at the end of life?

Vollmann, Jochen; Gather, Jakov

jochen.vollmann@rub.de

Physician-assisted suicide (PAS) is currently the subject of controversial discussion in many European countries – e.g. currently in Germany - , albeit only a few of them have legalized this end-of-life practice under certain conditions. For the main part, the people who ask for assistance in suicide suffer from incurable physical diseases. In rare cases, however, the suicide of patients who additionally or solely suffer from mental disorders is also assisted.

The aim of this contribution is to describe potential roles of psychiatrists in the context of PAS and to formulate ethical arguments for or against the respective involvement of psychiatrists in PAS.

Some authors argue that psychiatrists, invoking the social responsibility for suicide prevention, should strictly reject any involvement in PAS and offer a psychiatric treatment to patients with suicide plans. Others see the role of psychiatrists in assessing the patients' competence, which constitutes a fundamental prerequisite for PAS from an ethical point of view. Moreover, others deem a medical prescription of a lethal drug and the assistance in suicide by psychiatrists for ethically acceptable under certain conditions.

We argue that psychiatrists are particularly well-suited to differentiate autonomous and non-autonomous suicide plans based on their expertise in the field of suicidology and in competence assessment. From an ethical point of view, the involvement of psychiatrists can thus contribute to quality assurance of a legalized practice of PAS, benefit the patient autonomy at the end of life and minimize risks of abuse. However, that does not lead to a further medicalization of PAS, because although medical professions have certain medical tasks its' main role is assistance whereas the patient himself is the decision maker and actor.

Why the legitimacy of nudging needs to be empirically informed

Vugts, Anastasia; Van den Hoven, Mariëtte

Anastasia.vugts@wur.nl

Thaler and Sunstein's (2008) concept of nudging has led to a lot of ethical debate. Steering people's behavior, even when preserving the freedom of choice, is criticized for infringing on people's autonomy, as manipulative, as paternalistic even if people can opt out of the nudge that they are confronted with. For example, when people are being nudged toward the healthier food choice (say, a salad) in a supermarket or in a lunchroom, and they are still free to choose for the unhealthier food choice (say, a burger with French fries), this could still be perceived as interfering and manipulating. This is so because seemingly someone, other than yourself, decides what's best for you. At the same time, freedom of choice is only one aspect of autonomy, and others have suggested that nudging can promote or stimulate autonomy of those who are now weakly willed or 'bad choosers' as Thaler and Sunstein (2008) present it. Moreover, it can be argued that freedom of choice can be restricted while autonomy is still preserved (Sunstein, 2014). Different notions of autonomy are possible and at play in contexts where nudging is being discussed. It is not immediately clear which perspective on autonomy is correct or whether possibly different views on autonomy apply on nudges in practice. Therefore, these different notions of autonomy could lead to different views on the legitimacy of nudging. Currently we have limited data on the views of nudgees on autonomy; what do they see as infringing or empowering? A more diverse view on autonomy is important when reflecting on the normative question of the legitimacy of nudging. According

to Carter and Hall (2012) a broader discussion on the acceptability of nudges is required and this debate should not be limited to governmental initiated nudges for improving public health but should encompass all sorts of nudges. In this project we aim to discuss prototypical nudges in different contexts. Empirical findings will help to intensify the current debate on the infringement of autonomy and the acceptability of different types of nudges. We explore a dialogical approach; the so-called critical ethics approach (Leget, Borry, & de Vries, 2009) to inquire target groups of nudges. We will present a framework that involves a combination of psychological and normative questions that addresses the following questions: first, how do we need to understand autonomy in nudging discussions? And secondly, what will be core considerations to determine the legitimacy of nudging?

References:

- Carter, A., & Hall, W. (2012). Avoiding selective ethical objections to nudges. *The American Journal of Bioethics*, 12(2), 12-14.
- Leget, C., Borry, P., & de Vries, R. Nobody tosses a dwarf! The relation between the empirical and the normative reexamined. *Bioethics*, 23(4), 226-235.
- Sunstein, C. R. (2014). *Why Nudge? The Politics of Libertarian Paternalism*. Yale University Press.
- Thaler, R.H., & Sunstein, C.R. (2008). *Nudge, Improving decisions about health, wealth, and happiness*. New Haven, CT: Yale University Press.

Beyond EMB – A quaternary prevention view of the literature

Wagner, Hamilton Lima

hamiltonw@uol.com.br

Starting pointing that quaternary prevention is about caring patients with attention and the best quality of care available, avoiding the excess of medical intervention, which does not represents better care or increase in life or quality of life.

I came here today to propose a new qualification to research in health. We must have to believe in the information, and we are facing a huge challenge – the misconduct of research funders.

We are in a moment that sharing decision is mandatory to have good care, people are over informed about news and research at the internet. But this information is often inadequate and leading to bad practice.

In order to change this I'm proposing a kind of accreditation to a research that shows in advance the protocol that will be developed, and opens the raw data for independent researchers. This will allow credibility and reproducibility to every research we need to check, and will offer safety standards to medical practice.

We could work with the FDA, the EMA and the WHO, in order to propose this accreditation. After that we can push the medical magazines to recognize this accreditation as a gold standard.

I believe that with this simple initiative we can rescue evidence based medicine, that was corrupted by the business we face in health care, and could begun a new path do medical practice.

Risk and benefits of pediatric phase 1 trial in oncology. A systematic review

Waligora, Marcin, Bala, MM; Koperny, M et al.

m.waligora@uj.edu.pl

Phase 1 clinical trials based on pre-clinical data and animal toxicology are associated with the highest uncertainty. They remain, however, critical first step in a drug development. In oncology phase 1 studies are carried out usually on patients who previously received unsuccessful systemic therapy and for whom no standard therapy exist. The average age of patient participating in phase 1 trial is about 60 years old.

Despite the fact that cancer is mostly a disease of adults, it remains one of the major causes of death in pediatric populations. Because cancer in children differs from this in adults (e.g. children tumors differ histologically from adults') data based on pediatric trials are needed. Phase 1 pediatric trials in oncology almost always follow after initial testing in adults, and use starting dose defined in relation to adults maximum tolerated dose (MTD).

Because they involve populations that are unable to provide valid informed consent, phase 1 pediatric trials in oncology are ethically contentious. Further, there is uncertainty as to whether the risk/benefit balance in phase 1 studies should count as therapeutic.

A systematic review performed by Roberts et al. found that the overall toxic death rate for 213 phase 1 clinical trials from 1991 to 2002 was 0.54%, while the overall objective response rate was 3.8%. A systematic review for the same time period performed by Horstmann et al. found that the overall toxic death rate for 460 trials was 0.49 percent, while the overall response rate (for both complete and partial responses) was 10.6 percent. An analysis of study conduct efficiency of pediatric phase 1 trials in oncology, a systematic review performed by Lee et al. for trials published from 1990 to 2004 suggest that the number of toxic deaths are similar to adults phase 1 trials (0.5%) and objective response rate is 9.6%. A systematic analysis of 16 pediatric phase I trials conducted for children at the National Cancer Institute between 1992 and 2005 found that the overall toxic death rate was 0,4% and the complete and partial response was 4%.

In our study we will quantify the risk-benefit balance for phase 1 cancer studies for pediatric cancer phase 1 trials from 2004 to 2014, measuring benefit by response rate and risk by Grade 3,4, or 5 drug related events.

Funding was provided by the National Science Center, Poland, DEC 2011/03/D/HS1/01695.

Including children in their health care: Opportunities and challenges

Wangmo, Tenzin; De Clercq, Eva; Ruhe, Katharina et al.

Tenzin.Wangmo@unibas.ch

The last two decades have seen an increased recognition of the participation rights of children in choices regarding their own health. Due to children's developing nature, the pediatric context is characterized by a peculiar dynamic between three stakeholders: the minor patient, his or her parents, and the healthcare provider(s). This triadic relationship underscores the significance of the involvement of all parties in the medical communication as well as in the treatment decision making processes. Limited number of studies discuss children's own perception regarding their participation in healthcare. More information is available on the perspectives of parents and physicians.

This study aims to bridge this gap by describing the attitudes of physicians, parents, and pediatric patients living with cancer (age 9-17) concerning the participation of the minor patient in medical communication and decision making in Swiss pediatric oncology settings. For this purpose, data from semi-structured interviews with these 3 groups of participants (18

triads) was analysed qualitatively to identify themes revolving around opinions on inclusion and exclusion of children in medical communication and decision making, as well as reasons why children are excluded or included.

Results from these interviews report that although all three participant groups valued children's participation in healthcare, they found it important to evaluate the individual situation, preferences, and personality (rather than age) of each child. Also emphasized by our participants was the significance of considering children's accounts along with the perspective of others without either dominating the decision making process. Besides the instrumental value of better compliance with treatment when children are informed, the main reasons to include children were of a more intrinsic (ethical) nature: physicians and parents were concerned that not telling the truth would pose a serious threat to the trust relationship between children and their parents, and between children and their physicians. Moreover, since the illness and the treatment affects the children themselves, all parties stated that children thus have the right to know. The reason was that it was more frightening for the children to be left wondering what is happening than to know and thus understand it. Hence, facilitating children's inclusion helps them to "rise above imagination" and to become less anxious. The main reason for exclusion is to protect children from emotional stress, especially in the case of a bad prognosis.

Medicalisation as hermeneutical injustice: The case of medically unexplained symptoms

Wardrope, Alistair

ajbwardrope1@sheffield.ac.uk

Many of the most vociferous critiques of medicalisation present the process as an instance of *hermeneutical injustice* - a form of epistemic injustice that prevents people having the hermeneutical resources available to interpret and communicate significant areas of their experience.³⁹ Such arguments propose that medical institutions bear such overwhelming epistemic authority that, when a given phenomenon is modelled in medical terms, this model is taken to be the definitive description, thus rendering invisible aspects of the phenomenon (especially psychological or social dimensions) that may be less salient to its pathophysiological interpretation.^{40,41} In this paper, I propose to consider this line of argument in relation to the medicalisation of 'medically unexplained symptoms' (MUS), persistent physical complaints for which no consistent organic pathology can be demonstrated.

Examination of clinical encounters between health workers and patients with MUS, I argue, demonstrates that understanding the epistemic consequences of medicalisation requires more nuance than is often displayed in the hermeneutical injustice critique. Rather than being constrained to speak of their suffering within the conceptual framework of biological medicine, patients with MUS draw on a wide range of conceptual resources to interpret their experience, often themselves reshaping the medical framework itself, or employing medical terminology as a tool to frame non-medicalised interpretations.⁴² Moreover, such

³⁹ Wardrope A. Medicalization and epistemic injustice. *Med Health Care Philos.* 2014;1:1-12. doi:10.1007/s11019-014-9608-3.

⁴⁰ Illich I. *Limits to Medicine: Medical Nemesis, the Expropriation of Health*. Reprint edition. London: Marion Boyars Publishers Ltd; 2000.

⁴¹ Elliott C. *Better Than Well: American Medicine Meets The American Dream*. New edition edition. New York: W. W. Norton & Co.; 2004.

⁴² Peters S, Stanley I, Rose M, Salmon P. Patients with medically unexplained symptoms: Sources of patients' authority and implications for demands on medical care. *Soc Sci Med.* 1998;46(4-5):559-565. doi:10.1016/S0277-9536(97)00200-1.

interpretations readily admit psychological, social, and political dimensions in characterising their experiences.⁴³

However, these encounters also serve to highlight a different issue that, if not a hermeneutical injustice, constitutes at least an unwarranted hermeneutical privilege afforded medical institutions. The ostensible purpose of medicalising a given phenomenon is to identify its biological substrate such that interventions able to modify it with desirable consequences may be developed and applied. But the benefits to patients with MUS of their medicalisation appear entirely distinct from – and in some cases even opposed to – this *prima facie* purpose. Many instead seek primarily *explanations* of their suffering that serve to ‘legitimise’ it and to exculpate them from its consequences.^{44,45} That medicalisation plays for patients with MUS this role tangential to the intended societal function of medical institutions, suggests that these institutions are afforded an unwarranted hermeneutical privilege in determining which forms of human experience comprise legitimate forms of suffering, and what social roles different individuals should fulfil. I conclude by considering how acknowledging these divergent functions of medicalisation may help to prevent conflict between health workers and patients with MUS and enhance management of such conditions.

The medicalization of salvation

Welie, Jos VM

jwelie@creighton.edu

Throughout human history, there has always been a close connection between religion and medicine. Traditional medicine men or women were often also faith leaders; the Greeks had various Gods of medicine and health care and Hippocratic medicine was integrated into this religious cultus; the Christian bible contains many stories of healings performed by Christ and many religious orders exist that specifically devoted to health such as the Order of Malta and the Sisters of Mercy; and today the scholarly literature contains many publications on the links between spirituality and health. The few exceptions that defy this linkage, such as the earlier prohibition in the Catholic church’s canon law prohibition clerics from being physicians, or the modern insistence that medical science should be free of religious influences, make sense precisely as the proverbial exceptions that confirm the rule.

These linkages have also led to a blurring of the distinctions and even a usurpation of one by the other. Today, we are quite familiar with the way in which Christianity came to dominate all areas of life in the Middle-Ages, including health care. We could call this phenomenon the “religionization” of medicine. Religionization led to the provision of ineffective remedies, stifled scientific progress, and perpetuated damaging biases against different categories of patients as sinners or possessed – to mention only a few. These seriously flawed practices could persist for extensive periods of time because the same power of religion that enabled “religionization” in the first place also shielded it from criticism. Religion was, in effect, untouchable.

In this presentation, I intend to suggest that the modern phenomenon of medicalization shows some remarkable similarities with the medieval phenomenon of religionization, including some quite harmful consequences for religion itself, as exemplified in the title of this

⁴³ Fainzang S. The Other Side of Medicalization: Self-Medicalization and Self-Medication. *Cult Med Psychiatry*. 2013. doi:10.1007/s11013-013-9330-2.

⁴⁴ Salmon P, Peters S, Stanley I. Patients’ perceptions of medical explanations for somatisation disorders: qualitative analysis. *BMJ*. 1999;318(7180):372-376. doi:10.1136/bmj.318.7180.372.

⁴⁵ Nettleton S. “I just want permission to be ill”: Towards a sociology of medically unexplained symptoms. *Soc Sci Med*. 2006;62(5):1167-1178. doi:10.1016/j.socscimed.2005.07.030.

presentation. The format of a short breakout presentation will not allow for a detailed examination of this suggestion; instead, this suggestion will be illustrated in broad and intentionally provocative strokes to invite discussion. The presentation will be limited also in that only a comparison will be made between Christianity and western medicine/health care. The presentation is intended to be of interest to scholars who have a specific interest in the connections between medicine and religion but equally to those who want to keep both domains completely separated. For in the same way as Christianity was ultimately harmed by the process of religionalization, so medicine itself is likely to be harmed by the process of medicalization.

Philosophical tools for Quaternary Prevention (P4)

Widmer, Daniel

drwidmer@belgo-suisse.com

Quaternary Prevention (P4) is concerned with overmedicalization. What is the relationship between knowledge and P4 action? Far from a sceptical attitude, leading to therapeutic nihilism, P4 is based on a reflexive attitude using many epistemological tools ranging from positivism to critical theory, systemic theory, phenomenology, hermeneutics, psychoanalysis and constructivism. The reflexive attitude considers the balintian concept of apostolic function explaining maximalization of medical agenda conducting to disruptive medicine. Prudential P4 can recognize the importance of both principles of beneficence and non-maleficence and the interest to individual lived experiences.

Social egg freezing – A new medical technology and the challenges of modernity

Wiesing, Urban

urban.wiesing@uni-tuebingen.de

The presentation examines social egg freezing as an exemplary case of medicalization of reproduction under the conditions of modernity. More specifically, it focuses on offers provided by companies (Apple, facebook) to fund social egg freezing for their employees.

Social egg freezing finds support in the well-known motives of modernity: eliminating chance, expanding our range of freedom, compensating for biological disadvantages, self-fulfillment, and individualization. It allows for yet another way to exercise our control over nature and serves to overcome natural barriers. Additionally, it permits us to rationalize our way of life. And, so long as the welfare of the child in question is ensured, there are hardly serious reasons in a liberal society as to why social egg freezing should be banned.

Still, the documented success rates of egg freezing are much lower than expected by the women. For this reason, the presentation critically examines the success rates of egg freezing and answers the question as to how this technology can actually fulfill its promises.

Furthermore, there is a certain form of ambivalence typical of modernity that comes to reveal itself with social egg freezing. Having areas of life at one's command through technology is simultaneously accompanied by being commanded. In this way, the new option for women to extend their reproductive lifespan is accompanied by a further form of medicalization as well as the feeling of being somewhat obligated to take advantage of the opportunity that social egg freezing provides. At the same time, employers' offer to support social egg freezing has subtle normative effects on one's private and working life.

In this respect, different questions arise with regard to social egg freezing: Does egg freezing allow a woman to make personal, authentic decisions as to the timing of her pregnancy? Or does it compel women to allow their working life to further dictate their plans for the future? Both questions can be answered with a 'yes', and they are not mutually exclusive. The example of social egg freezing not only illustrates the unquestioned challenges and the ambivalence of modernity. It also serves as an example for the ambivalence of medicalization.

In a concluding note, releasement (*Gelassenheit*, Martin Heidegger) is discussed as a possible answer to the challenges of modernity.

Uterine transplantation: Should living or deceased donors be morally preferred?

Williams, Nicola J

n.williams2@lancaster.ac.uk

In recent years much work has been undertaken by scientists internationally regarding the feasibility of the human uterine transplant (UTx) as a potential treatment for absolute uterine factor infertility (AUI). Should it reach clinical application this procedure would allow such individuals what is often a highly desired opportunity to become not only social parents (via adoption), or genetic and social parents (through gestational surrogacy) but to become parents in a social, genetic and gestational sense. Like many other experimental transplantation procedures such as face, hand, corneal and larynx transplants, UTx as a therapeutic option poses risks to the health and life of the recipient and falls firmly into the camp of the quality of life (QOL) transplant, undertaken with the aim, not to save a life, but to enrich one. However, unlike most of these novel procedures: where one would be both unlikely to find a living hand, face, cornea or larynx donor or an ethics committee willing to sanction such a donation, the organs to be transplanted in the case of UTx are potentially available from both living and deceased donors.

In this paper, in light of the recent nine case research trial in Sweden which used uteri obtained from living donors and has so far resulted in three live births, and the assertions on the part of other research teams currently preparing trials of UTx that they will only be using deceased donors I explore the question of whether, in the case of UTx, living or deceased donors should be morally preferred despite the benefits that may be associated with the use of organs donated by living volunteers.

Bio-implants, self-management and the uncanny

Zwart, Hub

H.Zwart@science.ru.nl

Due to recent developments in technosciences, such as synthetic biology, tissue engineering and nanomedicine, our sway over the human 'condition', but now taken in its literal, biomedical sense, is increasing, down to the molecular level, and up to the point of becoming uncanny. New options for drug delivery and bio-implants are entering (pervading) human bodies and brains. On the one hand, this may be seen as strengthening human autonomy and agency, as physical obstacles may now be overcome more effectively than ever before. On the other hand, we must consider the possibility (articulated by Heidegger) that 'something else' is ruling this process, and that we (our bodies and brains) are the targets rather than the masters of this process. Rather than being in control, we may become increasingly dependent on these new technologies, emerging in the boundary zone between therapy and

enhancement. As Mängelwesen (deficient beings), exposed to the challenges of a competitive socio-cultural environment, we may be forced to go along with it. Concerns over this development will be probed with the help of the concept of the uncanny, coming from various sources. On the one hand Heidegger, who already referred to human technology as the uncanny. Question: now that implants are entering our own bodies, is technology becoming hyper-uncanny? On the other hand psychoanalysis: the uncanny as a boundary object (or bio-object) emerging in the boundary zone between living and non-living, external and intimate (or, as Lacan phrases it: 'extimate'), between embedded and foreign, artificial and natural. Are new technoscientific developments such as precision drugs and bio-implants uncanny par excellence? Will they reduce or increase discontent in civilisation? They allegedly promote self-management and practices of the Self (Foucault), but perhaps they rather represent the will to bio-power of the Other?

PARTICIPANTS

Surname	Name	Email
Abbey	Hilary	H.Abbey@bso.ac.uk
Ahlzen	Rolf	Rolf.Ahlzen@kau.se
Ahola-Launonen	Johanna	johanna.ahola-launonen@helsinki.fi
Anderssen	Jorid	jorid.anderssen@uit.no
Andorno	Roberto	roberto.andorno@rwi.uzh.ch
Anjum	Ranji Lill	rani.anjum@nmbu.no
Aquino	Yves St. James	yves-saint-james.aquino@students.mq.edu.au
Arnason	Gardar	gardar.arnason@uni-tuebingen.de
Arnason	Vilhjalmur	vilhjarn@hi.is
Arribas-Ayllon	Michael	Arribas-AyllonM@cardiff.ac.uk
Aurenque	Diana	diana.aurenque@gmail.com
Badcott	David	badcott@tiscali.co.uk
Banton	Amanda	a.banton@leedsbeckett.ac.uk
Barilan	Michael	ymbarilan@gmail.com
Barnet	Robert	phbobmd@gmail.com
Benaroyo	Lazare	lazare.benaroyo@unil.ch
Benton	Kathleen	kathleendeloach1@hotmail.com
Bessemans	Chris	chris.bessemans@ucll.be
Beyers	Fleur	F.Beyers@campusgelbergen.be
Boitte	Pierre	pierre.boitte@univ-catholille.fr
Borovecki	Ana	abor@mef.hr
Borrry	Pascal	Pascal.Borrry@med.kuleuven.be
Brandt	Reuven	r.brandt@lancaster.ac.uk
Brukamp	Kirsten	brukamp@gmail.com
Budin-Ljosne	Isabelle	i.b.ljosne@medisin.uio.no
Caenazzo	Luciana	luciana.caenazzo@unipd.it
Campbell	Michael	michaeldavid.campbell@utoronto.ca
Campo-Engelstein	Lisa	campoel@mail.amc.edu
Chanska	Weronika	weronika.chanska@gmail.com
Chima	Sylvester	Chima@ukzn.ac.za
Claire	Kim Junga	clairejungakim@gmail.com
Codato	Francesco	francesco.codato@unive.it
Corraza	Vera	vera.corazza@student.unisi.it
Curran	Dorothyann	dcurran@toh.on.ca
Cutas	Daniela	daniela.cutas@umu.se
Dahl	Ellen Stokken	ellensdahl@gmail.com
De Clercq	Eva	eva.declercq@unibas.ch
De Grandis	Giovanni	giovanni.de.grandis@ntnu.no
De Kesel	Marc	marcaugustdekesel@gmail.com
De Vos	Jan	JanR.DeVos@UGent.be

Surname	Name	Email
De Wert	Guido	g.dewert@maastrichtuniversity.nl
DeCoster	Barry	Barry.DeCoster@acphs.edu
Dehue	Trudy	g.c.g.dehue@rug.nl
Dekkers	Wim JM	w.dekkers@xmsnet.nl
Devisch	Ignas	Ignas.Devisch@UGent.be
Di Marco	Silvia	sdmarco@fc.ul.pt
Dierickx	Kris	kris.dierickx@med.kuleuven.be
Dollberg	Shaul	shauldol@gmail.com
Dranseika	Vilius	vilius.dranseika@fsf.vu.lt
Edgar	Andrew	Edgar@cardiff.ac.uk
Ehni	Hans-Jörg	hans-joerg.ehni@uni-tuebingen.de
Eichinger	Tobias	eichinger@ethik.uzh.ch
Feiring	Eli	eli.feiring@medisin.uio.no
Felzmann	Heike	heike.felzmann@nuigalway.ie
Feys	Roel	feys@email.sc.edu
Focquaert	Farah	Farah.Focquaert@ugent.be
Foreman	Tom	tforeman@toh.on.ca
Gaille	Marie	mariegaille@yahoo.fr
Gastmans	Chris	Chris.Gastmans@med.kuleuven.be
Gefenas	Eugenijus	eugenijus.gefenas@mf.vu.lt
Gelhaus	Petra	gelhaus@ukmuenster.de
Gerber	Berna	berna@sun.ac.za
Gjernes	Trude	Trude.Gjernes@uin.no
Gordijn	Bert	bert.gordijn@dcu.ie
Gunson	Darryl	darryl.gunson@uws.ac.uk
Grunt-Mejer	Katarzyna	kgruntmejer@gmail.com
Guntram	Lisa	lisa.guntram@liu.se
Haery	Matti	matti.hayry@aalto.fi
Halgunset	Vidar	vidar.halgunset@ntnu.no
Hendriks	Manya	manya.hendriks@usz.ch
Hens	Kristien	Kristien.Hens@kuleuven.be
Hofmann	Bjorn	b.m.hofmann@medisin.uio.no
Holm	Soren	soren.holm@manchester.ac.uk
Hoven, van den	Mariette	M.A.vandenHoven@uu.nl
Huebel	Sylvia	sylviahubel@gmail.com
Hughes	Jonathan	j.a.hughes@keele.ac.uk
Ienca	Marcello	marcello.ienca@unibas.ch
Jaarsma	Pier	pier.jaarsma@liu.se
Jamoulle	Marc	marc_jamoulle@runbox.com
Katzenelson	Edna	edna-k@013.net

Surname	Name	Email
Kearns	Alan J	alan.kearns@dcu.ie
Kekewich	Mike	mkekewich@toh.on.ca
Kerasidou	Angeliki	angeliki@well.ox.ac.uk
Kessler	Carla	c.j.kessler@uu.nl
Kimsma	Gerrit	gerrit.kimsma@radboudumc.nl
King	Nancy	nmpking@wakehealth.edu
Komparic	Ana	ana.komparic@mail.utoronto.ca
Konecna	Hana	hana@adamcr.cz
Lanoix	Monique	mlanoix@ustpaul.ca
Leissner	Jonathan	jomi6666@gmail.com
Levitt	Mairi	m.levitt@lancaster.ac.uk
Louhiala	Pekka	pekka.louhiala@helsinki.fi
Mahieu	Lieslot	Lieslot.Mahieu@med.kuleuven.be
Malmqvist	Erik	erik.malmqvist@liu.se
Materstvedt	Lars Johan	lars.johan.materstvedt@ntnu.no
McKeown	Alex	alex.mckeown@bristol.ac.uk
McLennan	Matthew	mmclennan@ustpaul.ca
Melse	Johan	Johan.Melse@rivm.nl
Mertes	Heidi	Heidi.Mertes@ugent.be
Miclot	Brian	miclotbrianj@sau.edu
Mills	Catherine	catherine.mills@monash.edu
Moerenhout	Tania	tmoerenhout@hotmail.com
Mumford	Stephen	Stephen.Mumford@nottingham.ac.uk
Murano	Maria Cristina	maria.cristina.murano@liu.se
Myskja	Bjørn	bjorn.myskja@ntnu.no
Neiders	Ivars	Ivars.Neiders@rsu.lv
Nortvedt	Per	per.nortvedt@medisin.uio.no
Novitzky	Peter	pnovitzky@gmail.com
Ouvrard	Patrick	patrick.ouvrard@unimedia.fr
Papagounos	Georgios	papagounos@gmail.com
Paranhos	Flavio RL	flavioparanhos@uol.com.br
Pegoraro	Renzo	renzo.pegoraro@fondazionelanza.it
Pennings	Guido	Guido.Pennings@ugent.be
Piessens	Veerle	veerle.piessens@scarlet.be
Podmore	Will	W.Podmore@bso.ac.uk
Polzer	Jessica	jpolzer@uwo.ca
Raus	Kasper	Kasper.Raus@ugent.be
Rawlinson	Mary	mary.rawlinson@stonybrook.edu
Rehmann-Sutter	Christoph	christoph.rehmann-sutter@unibas.ch
Rentmeester	Christy	christyrentmeester@creighton.edu

Surname	Name	Email
Rheinsberg	Zoe	zrheinsberg@web.de
Robeson	Richard	rich.robe@northstate.net
Rogers	Wendy	wendy.rogers@mq.edu.au
Rosati	Paola	paola.rosati@opbg.net
Rozynska	Joanna	jrozynska@gmail.com
Sahm	Stephan	stephan.sahm@t-online.de
Sandman	Lars	Lars.Sandman@hb.se
Sawada	Aiko	aiko@lime.ocn.ne.jp
Schermer	Maartje	m.schermer@erasmusmc.nl
Sedler	Mark	mark.sedler@stonybrookmedicine.edu
Shahvisi	Arianne	arianneshahvisi@outlook.com
Shandera	Wayne X	shandera@bcm.edu
Shimoda	Motomu	shimodamotomu@gmail.com
Simons	Caroline	simonsca@tcd.ie
Simonstein	Frida	fridas@yvc.ac.il
Singh	Neil	neilsingh15@googlemail.com
Skolbekken	John-Arne	john-arne.skolbekken@svt.ntnu.no
Skorsetz	Ulrike	Ulrike.Skorsetz@med.uni-jena.de
Slade	Ingrid	ingrid.slade@st-annes.ox.ac.uk
Smajdor	Anna	A.Smajdor@uea.ac.uk
Snijdewind	Marianne	m.c.snijdewind@amc.uva.nl
Solbjør	Margit	marit.solbjør@svt.ntnu.no
Somers	Sara	Sara.Somers@UGent.be
Specker	Jona	j.specker@erasmusmc.nl
Stempsey	William E	wstempse@holycross.edu
Sterckx	Sigrid	sigrid.sterckx@ugent.be
Stol	Yrrah	y.stol@erasmusmc.nl
Streeck	Nina	nina.streeck@uzh.ch
Stroobant	Joyce	Joyce.Stroobant@ugent.be
Stuart	Rennie	stuart_rennie@med.unc.edu
Sugarman	Jeremy	jsugarman@jhu.edu
Svenaesus	Fredrik	fredrik.svenaesus@sh.se
Sykora	Peter	petersykora111@gmail.com
Takala	Tuija	tuija.takala@helsinki.fi
Tamin	Jacques	drjsftamin@hotmail.com
Tengland	Per-Anders	per-anders.tengland@mah.se
Thompson	Alison	a.thompson@utoronto.ca
Tschaepe	Mark	mdtschaepe@pvamu.edu
Tyreman	Stephen	S.Tyreman@bso.ac.uk
Ui Chonnachtaigh	Sorcha	s.ui.chonnachtaigh@keele.ac.uk

Surname	Name	Email
Ulman	Yesim Isil	yesimul@yahoo.com
Van Assche	Kristof	Kristof.VanAssche@ugent.be
Van den Bogaert	Sarah	Sarah.VandenBogaert@ugent.be
Van Hoof	Wannes	wannes.vanhoof@ugent.be
Van Leuven	Sarah	Sarah.VanLeuven@ugent.be
Van Parys	Hanna	Hanna.VanParys@ugent.be
Vandersloten	Goedele	goedeleandersloten@hotmail.com
Vanheule	Stijn	Stijn.Vanheule@UGent.be
Vaswani	Vina	vina.vishkanya@gmail.com
Vegter	Mira	m.vegter@science.ru.nl
Vogt	Henrik	vogt.henrik@gmail.com
Vollmann	Jochen	jochen.vollmann@rub.de
Vugts	Anastasia	anastasia.vugts@wur.nl
Wagner Hamilton	Lima	hamiltonw@uol.com.br
Wagner	Angela Beatrix P	angelabpw@hotmail.com
Waligora	Marcin	m.waligora@uj.edu.pl
Wang	Fang-Yu	102523102@gms.tcu.edu.tw
Wardrope	Alistair	ajbwardrope1@sheffield.ac.uk
Welie	Jos VM	jwelie@creighton.edu
Widmer	Daniel	drwidmer@belgo-suisse.com
Wiesing	Urban	urban.wiesing@uni-tuebingen.de
Wijngaarden, van	Els	els.vanwijngaarden@phd.uvh.nl
Williams	Nicola	n.williams2@lancaster.ac.uk
Wilt, van der	Gert-Jan	GertJan.vanderWilt@radboudumc.nl
Zawita-Niedzwiecki	Jakub	jakub@zawila-niedzwiecki.pl
Zwart	Hub	h.zwart@science.ru.nl