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ABSTRACTS

The criminal physician and Raskolnikov – forever morally fallen?

Ahlzén, Rolf
rolf.ahlzen@kau.se

According to a widely held moral intuition, we ought both to expect and demand a higher general moral standard among practitioners of certain professions. These may include judges, lawyers, policemen, priests –and most certainly also the health care professions, and in particular physicians. We may understand this as an acknowledgment of the extraordinary trust that ill people need to invest in their physicians and the rights these doctors are given to intervene in extremely delicate matters, bodily and spiritual.

One consequence of this seemingly reasonable expectation is that physicians who fail morally may be judged in a harsher way than other professionals. Doctors committing serious crimes and being sentenced for them will stand the risk of being regarded as permanently and irreversibly unsuitable to perform their professional tasks.

I will present a number of reflections around this dilemma departing from Fiodor Dostojevsky´s *Crime and Punishment,* where the student Raskolnikov commits the murder of two women, one of which he owes a large sum of money. Raskolnikov is convicted and morally "healed" during a long-forced exile in Siberia, and by the love of the young saint like Sonia. Can we expect physicians convicted for serious crimes to be, like Raskolnikov, "morally healed" by their sentence? Or is this an irrelevant question, and we should rather conclude that a person who takes his or her punishment is by definition morally healed? Which arguments could support the hesitation to allow physicians who have, for example, committed murder or rape, to return to their professional tasks after their sentence is completed?

It will be argued that one may legitimately ask for some degree of evidence that a physician who has failed morally in a fundamental way is not necessarily suitable to return to clinical work unless it cannot, in some way, be shown that this person has passed through a process of the same basic sort as Raskolnikov did – a moral renewal.

Will the biggest implications be brought by the actual science or the discussion about it?

Ahola-Launonen, Johanna
johanna.ahola-launonen@aalto.fi

There is evidence that the discussion about neuroscience entails some biological reductionism and determinism. This takes place both in literature related to neuroscience, including neuroethics, and in public media and public discussion. In this view, more causal power to traits is attributed, for example, to genes than what the scientific consensus suggests in the present day of modern genetics and genomics. These beliefs have been related, for example, to the misuse of simplified explanatory models of genetics. Genetic determinism have also been suggested to be not only a result of misunderstanding or simplification of science, but potentially based on deep beliefs about social phenomena, namely, psychological essentialism believing in stable group behavior categories. Concentrating only to the biological part of the large phenomenon under research will produce insufficient and ineffective answers and applications to the issue at hand. Furthermore, reductionist and determinist thinking alters our conceptions of human beings and agency.

In this paper, I suggest that the scientific community, especially those studying the social and ethical implications of neuroscience, should take into consideration not only the implications that neuroscience might have, but also the implications that the very discussion related to neuroscience might have. It seems that implications are not restricted to the outcomes of the findings and applications of actual science, but they are produced by the discourse, too. What matters is not only the science, but also the ethical, social, and political meanings we give to it.

Pathologising Ugliness: An ethical critique of intersectional prejudice in aesthetic medicine

Aquino, Yves Saint James
yves-saint-james.aquino@students.mq.edu.au

The paper offers an ethical critique of aesthetic medicine's success at reframing physical features deemed 'ugly' as pathological. Aesthetic medicine, a collective label for medical specialties concerned with improving appearance, benefits from and contributes to the longstanding conflation of health and beauty norms. Aesthetic surgeons often appeal to vague notions of well-being and quality of life to promote the belief that a healthy body is a beautiful body, and vice-versa.

I first discuss the specific ways in which viewing the body simultaneously in health-related and aesthetic terms leads to pathologisation of ugliness. Ugliness can be associated with psychosocial problems, it can be depicted akin to (biomedical definition of) disability, or it can be explicitly re-defined as disease or disorder. Nowhere else is pathologisation of ugliness better exemplified than in the term 'aesthetic pathology', a contestable condition that, aesthetic surgeons argue, causes distress that can be 'treated' by surgery. Aesthetic pathology usually involves normative claims of inadequacy, excess, deformity or abnormality that are confirmed by cosmetic surgeons as undesirable. Through the notion of aesthetic pathology, surgical interventions are framed as corrective in the same manner as interventions for conventional diseases are understood.

Next, I investigate the ethical implications of pathologising ugliness. In particular, I draw from Margaret Olivia Little's notion of 'suspect norms of appearance' to evaluate the extent to which intersectional values of heteronormativity, whiteness and ableism merge in the medical definition of ugliness or aesthetic pathology. To facilitate the ethical critique, I offer the case of "Asian eyelids" as an example of so-called aesthetic pathology that can be modified through cosmetic surgery. Asian eyelids refer to the absence of upper lid fold that is typical among East Asians. Blepharoplasty, the surgical creation of upper lid fold, amongst East Asians illustrates a questionable cosmetic procedure that seemingly draws from an intersection of gendered, racialised and ableist prejudices.

Mind-reading, mind-hacking, and moral responsibility

Arnason, Gardar
gardar.arnason@uni-tuebingen.de

Advances in neuroimaging techniques, such as functional Magnetic Resonance Imaging (fMRI), increasingly help us identify neural structures and functions which have a role in decision-making and behaviour. Certain neural deficiencies or abnormalities may be correlated with dispositions to behaviours which violate social and moral norms. The oldest and perhaps best known case of this sort is that of Phineas Cage in 19th century, long before we had other means to observing the brain than opening the skull and take a direct look. These possibilities indicate that immoral/illegal behaviour may be excused by way of neuroscientific evidence. It seems that we can increasingly find neuroscientific evidence to excuse or exculpate specific acts or behaviour that violate social or moral norms, possibly to the extreme that almost every immoral or illegal act may have a plausible excuse even within a retributivist framework (that assumes that we generally have free will and are responsible for our actions). Not only neuroscientific observations, or mind-reading, can affect attributions of moral and legal responsibility. Direct neuroscientific interventions can also influence our behaviour in ways that removes or questions attributions of responsibility. This can happen in various contexts, such as in the case of therapeutic interventions like deep brain stimulation (DBS), or as a consequence of neuroenhancement. The main focus here, however is the possibility that brain-computer interfaces (BCIs) will be vulnerable to external interference, hacking, where someone can influence or control behaviour, mental states or perception of another—or herself—through a BCI. This is partly a security issue, which has received some attention recently both in academic publications and the media, but it also raises questions about responsibility as such manipulations endanger freedom. Responsibility is jeopardized also where manipulation of the brain does not determine behaviour, but influences it, even to the extent that the subject identifies with the resulting mental states and actions. As a result of these developments, a call has been made recently for considering "cognitive liberty" a basic human right.

Paternalism, consumerism or something else?

Árnason, Vilhjálmur; Hjörleifsson, Stefán; Lea, Kjersti
vilhjarn@hi.is

When people find their own resources for taking care of their health to be insufficient, they have the option of seeking medical help. This introduces the professional perspective of the healer, by definition different than the perspective of the patient herself: If the perspective of the healer was the same as that of the patient, the healer would not be able to provide any help and the patient would not consult with the healer in the first place.

The fact that the patient experiences a need for professional help does not imply, however, that the patient's own understanding of her state of health becomes redundant. To the contrary, the idea that the doctor alone has the resources to understand and manage the patient's problem is considered to be outdated and unacceptable. On the other hand, prevailing conceptions of patient autonomy and patient-centeredness that have been brought to the fore as alternatives to medical paternalism are problematic because they do not adequately describe the interplay between the patient's perspective and that of the professional.

We will provide a detailed case story that demonstrates the tension that can arise between a patient who requires certain examinations and a doctor who considers that these examinations are unlikely to be of help and that they may even be harmful for the patient. The patient in our case story finds it offending that the doctor does not want to accommodate his requests. This patient desires a healthcare system organised around consumer choice and the ability to pay rather than professional judgement and welfare state solidarity. The doctor is equally frustrated and finds himself longing for sovereign power to grant or refuse examinations and treatment, even if he knows that this paternalistic position has become untenable in today's political and moral landscape.

We believe it would be useful to conceptualise medical consultations and healthcare delivery in ways that supersede the antagonistic ideas of professional paternalism and consumerist autonomy as exemplified in the case story. We will analyse the meeting of a patient and doctor from a hermeneutic perspective and introduce Hans-Georg Gadamer's idea of "fusion of horizons" as a way of understanding the goal of medical consultations. We will apply Gadamer's theory to the case history that we present and argue that a healing relationship requires both parts to share a common purpose. Even when the point of departure of the doctor and the patient is quite different, both will have to commit themselves to a common cause and seek some kind of "fusion". However, we also argue that in order to capture the different knowledge, values and obligations of doctors and patients and more aptly describe their interplay, Gadamer's ideas need to be supplemented by Eric Cassell's understanding of "controlled conversations". While that notion lends itself well to analysis of sick persons, we ask whether our patient, who is not suffering badly, can be truly committed to entering a therapeutic relationship and which challenges that brings to the doctor.

The Power of the #Hashtag: Empowering and Silencing Stories

Aultman, Julie M
jmaultma@neomed.edu

From the #MeToo movement in the United States (e.g, #MeToo#Weinstein) and UK (#Westminster), initiated by primarily white, wealthy, and powerful women to expose sexual harassment and abuse, to the trans-european project, #HelpCalais, sparked by celebrities who harnessed the goodwill of the public to effectively bring aid to refugees in Calais, hashtag activism and the narratives created within have the power to ignite meaningful and revolutionary change in the world. Yet, despite the good intentions and positive outcomes of these social media movements, such as promoting awareness and volunteerism, they equally have the power to marginalize groups, silence the stories of those less privileged, and quash genuine activism and action. For example, Dan O'Shea, a counter-insurgency expert, described the social media response to the hundreds of missing Nigerian girls abducted by Boko Haram (#BringBackOurGirls) as merely a symbolic gesture that did not translate into meaningful action. Critics, such as O'Shea, have argued whether the hashtag movement works or not (i.e., leads to action) as a form of activism, and to what extent. However, the purpose of this presentation is to take the criticism a step further and illustrate how this form of digital activism and the narrative agency within (Yang, 2016) promotes the creation of a single, unsustainable, and often "broken" or dishonest story that harms - even when simultaneously doing some perceived good (e.g. promoting solidarity). While digital activism promotes a type of dynamic storytelling, with a flurry of single words, phrases, gifs, pictures, and brief embedded stories under a "#" or a set of interconnected hashtag phrases, the collective story that emerges is one that challenges traditional narrative structure, perpetuates stereotypes and ignorance, and creates a competitive, often disingenuous platform for its contributors to be heard. Furthermore, I argue hashtag activism has the power to silence or discourage persons from sharing their stories, including counter-narratives, which may be essential for thwarting the harm done by the single story (Adichie, 2009), and to effectively make change beyond the boundaries of cyberspace.

The value of homeopathy: more or less than meets the eye?

Badcott, David
badcott@tiscali.co.uk

Is the jury out or no longer that interested in subjecting homeopathic claims to scientific scrutiny? Homeopathy has been practised on an increasingly wider scale since its introduction by Samuel Hahnemann in the late 18th century and enjoys substantial public support in many countries. It has the "virtues" of supposedly being holistic, treating the whole person and in limiting dosages to unbelievably small amounts. The theory indicates that (a) small doses of substances producing illness symptoms can be used to treat those suffering from a similar disease and (b) that highly diluted solutions possess "memory". At the same time, it apparently flies in the face of conventional allopathic medicine and scientific method with its fundamental claim of "memory" and progressively enhanced therapeutic potency at increasing dilution.

Some scientists have pursued investigations which might have a positive bearing on homeopathic credibility. The pharmacologist/toxicologist Edward Calabrese (2008) has long promoted the concept of *hormetic* dose response (stimulation at low dosage/inhibitory response at higher dosage) and others report the influence of single ions on water molecules indicating sensitivity at 10,000 times greater than previously thought and the possible influence of nanoparticles. Luc Montagnier, a Nobel Prize Winner for discovery of the AIDS virus has been associated with controversial claims concerning water *memory*: "High dilutions are not nothing. They are water structures which mimic the original molecules". Montagnier now works at Jiao

Tong University in Shanghai China where work is focussed on a “new scientific movement” at the crossroads of physics, biology and medicine.

Numerous papers have been published that are intended to discredit homeopathy on theoretical grounds, lack of valid clinical studies or the inherent dangers of misleading patients suffering from serious medical conditions. And there are recent signs that some health authorities are beginning to adopt a less tolerant stance. In 2015, the National Health and Medical Research Council in Australia concluded that: “There was no reliable evidence from research in humans that homeopathy was effective for treating the range of health conditions considered” and following a critical UK parliamentary report a decision has been taken to disallow homeopathic treatment from National Health Service funding. In the United States the FDA has decided to regulate the $3 billion-dollar industry.

So, should homeopathy be classified as “pathological science”, something delusional and potentially harmful? Or do more recent studies open the door, if only slightly to a paradigm shift in understanding? And indeed, following John Stuart Mill to what extent should patients be protected from treatments that they themselves believe to be worthwhile? The paper will attempt to unpack and consider the major elements of this complex situation.

Communicating Animal Research: Trust, Institutional Openness and Risk in the European Union

Barnfield, Graham
gbarnfield@googlemail.com

The proposed paper builds on existing empirical work into the self-reporting performed by institutions – government, private and charity sector – into their use of animals in biomedical research. Under a recent EU Directive – and sometimes as part of the stricter laws permitted within individual Member States – such entities are obliged to publicly acknowledge their experimental use of animals, from insects to higher primates. Other key details include the quantity, species and care arrangements of such animals. Some organisations see this as a necessary evil to undermine animal rights groups which allege a culture of secrecy; others more fully embrace the ‘transparency’ agenda.

The aim of the paper would be to build on a current/unpublished project which evaluates and grades the online profiles of a representative sample of such organisations, by measuring the extent to which their public-facing websites accurately report on their use of animals in a clear and accessible fashion (in the process, complying with the revised EU Directive brought out in November 2017). By rigorously evaluating such websites, in terms of, for example their use of photography, non-technical case studies and online navigation, the paper would aim to identify the extent to which EU transparency guidelines on animal research transparency are being adhered to across EU Member States.

Whereas the empirical thrust of the paper considers the actual content and appearances of the sites involved, the materials assembled permit discussion of a wider question: namely, to what extent is the desire for openness expressed in the revised EU Directive and the voluntary Basel Declaration (2010) turning transparency into a normative principle linked to biomedical research?

Illness, Suffering and Dignity: Ethical Implications for care

Barugahare, John
jbarugahare@chuss.mak.ac.ug

Background: The primary *cause* of medicine and its practice is a moral responsibility to relieve suffering. Consequently, the corollary moral obligation for health care professionals is to alleviate suffering. In our ordinary understanding of suffering that calls for medical care suffering is occasioned by illness/disease, loss of function and the like. Indeed, it has been rightly observed that “None are more concerned about the relief of pain or restoration of lost function than physicians”. Unfortunately, accounts of the nature of suffering from experiences of some physicians stretching at least three decades back raise concern about health care professionals’ extent of understanding of the nature of suffering. Sadly these narratives reveal that irrespective of their noble intentions, physicians not infrequently cause avoidable suffering in their attempts to relieve it. In part this is attributed to physicians’ inaccurate grasp of the nature of the suffering. In their view such knowledge comes through thorough understanding of “the personal and social meanings of illness” which in turn depends on understanding the human condition or *the person* in a sense of personhood. **Discussion:** This paper discusses one of the dimensions of suffering called – *loss of dignity*. Right from ancient practice of medicine epitomized by the Hippocratic Oath to contemporary ethics principles of biomedicine, the preservation of human dignity is quintessential to good medical practice. In medical literature, the centrality of dignity is reflected in demands of privacy, confidentiality, autonomy, among others violation of which constitutes harm/suffering. The paper will show how loss of dignity or related perceptions are a category of deep suffering and threats to dignity that may exist in health care practices can even compound physical suffering. Illustrations from concerns about dignity, particularly in women’s health, are given as a hint on how health care professionals and the circumstances they work in sometimes cause avoidable suffering in an effort to alleviate it. The paper draws concerns and illustrations from the Ugandan Health care system on what can be observed and what has been widely *alleged* and *suspected* by patients about what they consider to be avoidable loss of dignity. Ultimately, the paper builds a case for health care actors’ (professionals and policy makers) special ethical obligations to assure the most minimum violations of *human dignity* or perceptions of such losses among patients. **Conclusion:** The paper concludes with an emphasis of the urgency of an empirical study of the subject of human dignity in health service delivery in Uganda, particularly threats to, and opportunities for human dignity and how this may affect acceptability and uptake of health services.

Replacing surrogacy by uterine transplantation? A critical analysis of arguments from an ethical perspective

Beier, Katharina
Katharina.Beier@medizin.uni-goettingen.de

Uterus transplantation is increasingly presented as a new path of treatment for women who cannot conceive children due to uterine insufficiency. First live births of children after uterine transplantation in Sweden have stirred an international debate on the ethical acceptability of this procedure. A major challenge results from the linkage of transplantation medicine with medically assisted reproduction. While both fields raise ethical issues of their own, uterus transplantation does not only inherit the latter ones but also raise new questions. For example, in contrast to transplantation of other organs, recipients use the donated uterus only temporary for the purpose of reproduction; afterwards, it becomes removed by hysterectomy.

While most of the discussion on uterus transplantation is concerned with the evaluation of risks, my talk takes a different starting point. In particular, I will examine the ethical justifiability of treating uterus transplantation as (future) substitute for gestational surrogacy. In fact,

comparisons between these two practices are frequently drawn (Grynberg et al. 2011; Robertson 2016; Testa et al. 2017). However, the mere fact that both procedures allow reproduction for otherwise infertile women does not imply that these practices are on equal footing, let alone, that uterine transplantation would be superior to surrogacy.
After a short explanation of the practices of gestational surrogacy and uterine transplantation, I will outline selected arguments that are used to suggest the substitutability of surrogacy by uterine transplantation and discuss their underlying assumptions from an ethical perspective. Specifically, I will examine arguments that focus on existing legal barriers to surrogacy, burden-shifting in order to receive a child of one's own and challenges of commercialization. Instead of solving these issues, my analysis will show that uterine transplantation cannot be seen as solution to specific issues of surrogacy but raises problems of its own. This becomes most visible when comparing the role/situation of women in both settings. While this does not speak against uterine transplantation, there is at least reason of not representing it as the per se "better option".

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Conceptualising privacy in a digital health care setting

Bernaerdt, Jodie
Jodie.Bernaerdt@ugent.be

Privacy is shaken up by the digital revolution in society, in which information about ourselves is collected, stored and shared on a large scale. Recently in healthcare, information technologies such as electronic medical records (EMR), wearables and health applications emerged. The digitalization in healthcare (e-health) holds the promise to improve efficiency and quality in healthcare and to provide personalized and evidence-based medicine (Eysenbach, 2001; Meier et al., 2013). Foremost, e-health generates and discloses an immense amount of medical and health related data. Patients become more transparent because their medical data are shared not only with care providers, but also with third parties, like private and public researchers (Bahr & Schlünder, 2015). Hence, the collection of medical data is not solely used for the intent of taking care of a patient's health, but also for purposes that are not the initial reason for which these data are collected – the so called secondary use of data. One can wonder if informational privacy will become obsolete in the 21st century.
Sharing medical data from the electronic medical record (EMR) challenges one of the basic ethical values in health care: patients' privacy. However, there is no consensus on the meaning of privacy, ergo there is no consensus on what counts as a privacy violation. Because information technologies will continue to shape our health care system thoroughly, it is important to think through what privacy means in a digital health care setting. In this presentation, we will explore the ethical aspects of informational privacy in healthcare by analysing the key components involved in sharing patients' medical information. These components will form the base to discuss how we should conceptualise privacy in a digital health care setting.

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Narratives about death and dying in Croatia

Borovecki, Ana
ana.borovecki@mef.hr

The patient's story is important for the day-to-day work of a doctor. From her we discover a lot about the patient and his family. The story and storyline of a patient's story can sometimes play an important role in making ethical decisions in medicine through the concept of narrative ethics. In everyday clinical practice, narrative ethics is applied through the understanding of the story and characteristics that make up the identity of the patient. This approach can help improve communication and decision making and ensure ethical care and patient welfare. If we use stories as a tool for understanding, negotiating, and understanding the situations we face in everyday life then knowledge of narrative ethics is important and necessary. If we understand how we think, feel, and interact with society through stories, then we also learn about ethical betting the world with others, which is the appropriate foundation for many of our relationships with others

The paper will present various ways of using narratives in ethics teaching. A short overview of a different approaches used in teaching will be presented which explore narrative elements in medicine, literature, ethics and physician patient relationship. Special focus will be given on themes related to death and dying. Themes will be presented from the perspectives of teachers involved, examples of text from the history of literature used. Additional narrative elements in teaching ethics will be explored through analysis of student essays which explore the themes of death and dying. These narrative elements found will enable us to construct the picture of narrative elements connected with death and dying in Croatia since the narratives will come from ethnologists and historians of literature (teachers), nursing students and medical students. This will be juxtaposed with research currently done about ethical decision making in Croatian ICU units and previous research done in Croatia about ethical decision-making at the end of life.

What the “Hunter Gracchus” story teach us about illness and dying

Caenazzo, Luciana; Tozzo, Pamela; Pegoraro, Renzo
luciana.caenazzo@unipd.it

A key benefit of publishing illness narratives, that gives voice to the sick and the dying in an different manner, has not only much to teach us about how we came to speak our illness and our agonies but offer fresh protocols to approach what may be the difficult concept of “a good death” (a good way to die).

The following considerations arise from the reading of Franz Kafka’s incomplete short story "The Hunter Gracchus" (1917) and, in particular, from the condition in which he puts the protagonist, the Hunter Gracchus.

Kafka creates a story on a theme whose realistic connotations were not clear at his time that is the artificial extension of the persistently compromised vital functions of a person, affected by an irreversible pathology, sometimes conscious, distressed and suffering just for living the dying process diluted in the time.

In our opinion "The Hunter Gracchus" seems to constitute a great opportunity to propose an approach to the problem of the "dehumanization" of dying.

Kafka creates a completely surrealistic story on a theme whose realistic connotations were not clear at his time, that is the artificial extension of the persistently compromised vital functions of a person, affected by an irreversible pathology, sometimes conscious, distressed and suffering just for living the dying process diluted in the time.

We consider this story as an approach to the problem of the "dehumanization" of dying in which the hunter's point of view acquires a particular value in relation to the feelings of the health care professional involved as a reader.

Reading this story, in our opinion, it is suitable to avoid adding words of "wisdom" to comfort one thesis or another, and it is better to give voice to the Poet, particularly when its sensibility picks the point of view of the person who suffers and when, above all, this point of view appears reliable, since the sensibility on which it is based is related to the experience of suffering like the life has reserved to Kafka himself.

Because narratives are intrinsically therapeutic and palliative, offering these opportunities could encourage the healthcare professionals to reflect on and communicate their feelings about adjusting to hospitalization, illness and treatment, and patient dying.

Altruism and compassion training in healthcare: a Christian perspective

Calderon, Pacifico Eric E
pacifico.calderon@dlsu.edu.ph

In his apostolic letter *Salvifici Doloris* on the Christian meaning of human suffering, Saint John Paul II counsels us that suffering is part of the mystery of man. For healthcare professionals, the parable of the Good Samaritan presents the call to compassion in concrete terms. In the Christian tradition, we learn the genuine meaning of compassion from the model of Christ's ministry when He broke through the barriers of sickness and sinfulness in order to encounter and heal the afflicted. As followers of Christ, we are called to make a preferential option for the poor and the vulnerable. A genuinely compassionate behavior is complex nevertheless, in that some people seem to be very attentive to the needs and concerns of others, while others seem oblivious and uncaring. Healthcare professionals similarly become susceptible to such "compassion fatigue," often overwhelmed by the needs and troubles of others to the point of becoming numb to suffering. Recent studies report an "epidemic" of compassion fatigue among healthcare professionals, an issue that may seriously affect the quality of care patients receive. To address this challenge, the author posits that healthcare students and clinical trainees can be taught to nurture others while developing a compassionate instinct. Introducing specific programs and initiatives to their education and training may facilitate altruism and compassion development over time. In this presentation, the author aims to identify key strategies to achieve this end. The process entails patience, steady care, proper tools, and a supportive environment. Compassion and mercy are rooted in the fundamental recognition of human dignity and integrity. Realizing the basic goodness of our personhood as God has created it is key to altruism and compassion development.

What alliance is possible between medicine and humanities? A proposal based on Kurt Goldstein's « holistic » conception of medicine

Camus, Agathe; Gaille, Marie

agathecame@gmail.com

In the field of contemporary philosophy and more broadly, in the Medical Humanities, it is argued that what is needed is to place the patient's experience at the centre of the questioning of medical practice: this experience should be taken into account by the medical community or nursing staff, and it can be described. Accessing the patients' accounts of their experiences, their illness narratives, is, in this perspective, decisive. An abundance of literary sources has made this turn possible as well as philosophical reflections, especially led in regard of chronic and degenerative diseases.

However, despite the importance of this perspective, one may observe that in the argument which advocates integrating the viewpoint associated with lived experience, the medical viewpoint's is seen as "the guilty party". To us, a revision of this position is necessary, in order to make progress towards an alliance between medicine and philosophy, such as advocated for by A. Mol, rather than an opposition. It is also necessary in order to be able to acknowledge the role played by some figures form whom anthropology, medicine and philosophy were not separate branches of the reflection.

In order to contribute to this acknowledgment, we would like to propose a comment upon the trajectory and conception of one of such figures: Kurt Goldstein. It drives us back to an era prior to the formulation of such a turn, characterized by different professional positions and discourses, an era in which the philosopher and the physician may be one and the same person and ambition to propose an anthropological understanding of medicine. As a matter of fact, Kurt Goldstein himself drew on philosophical thinking in order to elaborate his "holistic" conception of medicine. When reading his works, we are thus faced with an approach that breaches professional and disciplinary borders and questions them. We set two goals to our presentation: first, understanding the meaning of his holistic conception and its scope for a contemporary reflection on the relationship between humanities and medicine; second, highlighting how this alliance between anthropology, medicine and philosophy must be deciphered in the language used by Kurt Goldstein in his writings, in which many words and phrases can be read both by a neurologist and a philosopher today and interpreted in different ways by them. To illustrate this writing as a biologist, a physician, a philosopher, and an anthropologist, we will focus on Human nature in the light of psychopathology.

The Reality of Subliminal Pain

Correia, João Calinas
j.calinas.gp@gmail.com

Clinical practice shows us that conversations about pain are intrinsically difficult, with frequent stops required for the management of conceptual discrepancies: "no, it's not just in your head", "no it's not because you're depressed", "no, it does not imply damage", etc. The heterogeneity of pain concepts is widely acknowledged and disparaged. Together with the open-ended view of pain as whatever is experienced as painful, the resulting indeterminacy of pain complicates clinical encounters and pain research.

Aydede, while affirming the mainstream view (pain must be apparent to the one in pain, and the granted reality of such pain), nonetheless considered the pain that wakes us up: is it arising with the awakening (and thus not causing it) or precedes the awakening (in which case it was present before conscious experience)? The implication is the separation between the reality of pain and it being present to attention or self-awareness. The real issue, however, is about the reality of 'non-conscious experiences': events that do not grasp our attention although they have effects upon us at cognitive, affective and homoeostatic physiological levels. The robust evidence for the reality of unconscious experience is summarised. Subliminal events, and particularly blindsight, offer a curious window into the nature of unconscious experience. The onus is on pain to justify itself being an idiosyncratic form of experiencing that formally requires real-time awareness of the event.

The consideration of a subliminal presentation of pain has wide-ranging consequences.

Firstly, not all pains can be subliminal, e.g., ‘first pain’ is designed to grasp our attention as a discrete event; therefore, the possibility of subliminal pain requires physiological categorisation.

Furthermore, subliminal pain as motivation for behaviour appears similar to other emotions operating below self-awareness. ‘Disgust’, one such emotion, acts jointly with pain to motivate the ‘behavioural immune system’. The physiological characterisation of subliminal pain does open some aspects of its connection with disgust.

There is good evidence on the connection between disgust and social/political behaviour, as there is for pain, therefore the possibility of subliminal experiencing of pain, in the context of the increasing sensitivity to pain, opens interesting questions for the social sciences.

A brief selection of commentaries on the concept(s) of pain will be approached from the perspective developed above, including: pain without painfulness; need-state/imperative views on pain; unpleasantness/algosity duality; etc.

Finally, a brief overview of the physiological correlates of the developmental role of pain is contrasted with the physiological categorisation of subliminal pains. The areas of convergence and divergence are considered, looking into further avenues for investigating of the nature of pain.

Study on Confidential Birth and Safety Measures of Infants from Unmarried Mothers in South Korea

Choi, Yeani
xwwjdx@snu.ac.kr

In historical perspective, infant abandonment is not a new phenomenon. From ancient Greeks to biblical times, infant abandonment, regardless of its motivation, was always part of the society. Ever since foundling wheels resurfaced as the Baby Box, an anonymous relinquishment of infants at designated safe locations, they have stirred up ethical dilemmas wherever they were established. Despite the good intention of saving lives of infants from infanticide, rights of mothers who wish to remain anonymous and rights of children who wish to know their biological origins became conflicts of interest in many countries practicing one of many models of the Baby Box. In few countries, the Baby Box naturally evolved into a confidential birth system. Although French remained fully supportive of mother’s anonymity in respect to their private lives, Germans brought forth the confidential birth system where the confidentiality of the mother is fully secured only until the child turns sixteen. After sixteen, the child is granted with a right to seek the court about his biological information. Safe Haven Acts of United States grants mothers immunity from persecution and anonymity only if infants are left unharmed. However, Japan and Korea share great extent of similarities in cultural and legal context when dealing with the infant abandonment. The only Baby Box facility available in Korea accepted more than 1,000 infants since its establishment in 2009. The number is greater than any other countries operating the Baby Box facility. Therefore, by comparing historical, cultural, legal and ethical context of each country and various forms of safety net for the issues pertaining to infant abandonment, Korea’s current Baby Box system, and its relevant issues must be thoroughly evaluated. Korea’s Special Adoption Law, amended in 2012, is particularly examined in regard to the issue of increased infant abandonment rate because it has been considered as an active governmental initiative to increase the domestic adoption rate to compensate for its low birth rate. Despite vigorous governmental measures to increase fertility, South Korea marked the lowest birth rate among Organization for Economic Co-operation and Development (OECD) countries in 2016 and remains to be one of "ultra-low birth rate societies" since 2001. While the low fertility problem poses a great threat to global health, increase in incidences of non-marital births in Korea is particularly raising an important public health concern for unmarried pregnant women residing in Korea because they are often faced with public shame, neglect, and inequality in care and support they deserve which eventually encourage them to give birth in non-clinical setting such as public restroom and relinquish their infants at the Baby Box. The establishment of the Baby Box in South Korea can be a lesson for other countries suffering from high incidence of infant abandonment while disparity is prevalent among non-married single mothers.

A Multi-Method Approach to Evaluate the Current Views on Genetic Testing for Specific Learning Difficulties

Courtright-Lim, Amanda
Courtright-LimA@cardiff.ac.uk

Society takes account of both an individual's (dis)abilities and their genetic constitution in attributing value to them; it does not simply accept those with disabilities as valued members of our society. The project reported here is examining the ethical perspectives on genetic testing for learning disabilities, also known as specific learning difficulties (SLD). These are impairments that solely affect an individual's ability to perform a specific mental task (e.g. reading, arithmetic). Common disorders, like Dyslexia, are all non-visible disabilities typically diagnosed during schooling. Although SLDs can affect how an individual learns, they typically do not impact other aspects of a subject's life. These features of SLDs, along with the fact that genetics has only indicated genetic risk factors rather than clear causes, mean that genetic testing cannot predict the development of a disability. Ethical questions arise concerning the implementation of genetic testing for these disabilities, especially if testing is not implemented correctly or if its results, and the implications of those results, are not interpreted appropriately. These issues may be anticipated with a combination of qualitative and quantitative research.

Qualitative research has been conducted, consisting of semi-structured interviews with individuals experiencing SLDs first hand, either being affected or being parents of diagnosed subjects. Respondents have provided narratives of their lives being directly influenced by an SLD. These narratives have uncovered themes that demonstrate specific ethical issues associated with different forms of genetic testing from a personal perspective. These issues have been used to develop a quantitative online survey of the wider population that is being used to gather views on genetic testing for SLD as well as metadata of the survey participants, which allows for the possibility of exploring demographic factors that influence their views, such as age and occupation. Integrating the findings of these qualitative and quantitative enquiries will generate important insights into the ethical issues raised in relation to genetic testing for the SLDs.

Upon full analysis of the data set, the model of discourse ethics, by Jürgen Habermas, can then be utilized on the data to open up conversations about implementing different forms of genetic testing. After conversation has begun, the necessary steps can be taken to consider policies, guidelines and public engagement that would assist with anticipating the outcome of genetic testing and implementing it in a way that would not undermine or distort the value of individuals with SLDs.

The aim for my presentation will be to summarize my results from the qualitative research and semi-structure interviews, and to highlight the ethical issues that were identified and used to design the quantitative portion, online survey, of the project. I will provide the preliminary analysis from the online survey of the wider publics and highlight how these results alongside the data from the interviews will have implication for an ethical theory and future policy around genetic testing for SLDs.

The Latin American Social Medicine Movement: *Buen Vivir* and Collective Health

Crombie, James
james.crombie@usainteanne.ca

On the premise that there is such a thing as a distinctively Latin American Social Medicine movement, this paper is an exploration of a number of strands observed among thinkers associated with this movement. One of these strands is articulated around the thought and work of the Argentinian Juan César García (1932-1984) and, among other elements, his proposed renewal of thinking about the health-disease-treatment process (PSEA - *proceso de salud-enfermedad-atención*). Another, related strand is articulated around a characteristic notion of *living well* ('*buen vivir*' in Spanish, '*sumak kawsay*' in Quechua or '*suma qamaña*' in Aymara) in the thought of (among others) the Ecuadorean Alberto Acosta Espinosa (born 1948), inspired by the traditions of the Andean original peoples. A third strand is related to the work in the area of public health and prevention of violence by the prolific Colombian Hector Abad Gómez (1921-1987). The approaches underlying the scientific work and social influence of the Brazilian Oswaldo Cruz (1872-1917) and his successor as director of their important research institute at Manguinhos, Carlos Chagas (1879-1934), will also be examined. While a number of differences can be noted, what these different strands of thought have in common is a holistic and collective approach to health, with an emphasis on collective action and social change as means by which the health of populations can be improved. For Juan César García, references include Everardo Duarte Nunes (2015, etc.) and Galeano, Trotta & Spinelli (2011). For Hector Abad Gómez, references include Luz Adriana Ruiz Marín (2015).

Sci-Fi parenthood and the end of love

Cutas, Daniela
daniela.cutas@umu.se

News about ever more sophisticated ways to become parents raise concerns in terms of, among others, the increasing medicalisation of some of the most intimate forms of human interaction, as well as the decrease in willingness to accept risks in human reproduction. Prospects such as in vitro created gametes or reproductive cloning and the correlative possibility that a person reproduces without genetic material from someone else evoke transgressions of maybe the last frontier in human reproduction: that it is essentially collaborative. The increasing capacity to detect and eliminate any abnormality in embryos creates expectations of and from parents to pursue such technologies and make the "right", "responsible" choices. In turn, this surrender has been criticised for demonstrating defects in parental expectations and, ultimately, in parental love. Innovations in technologies of human reproduction take us further and further from culturally entrenched ideals of romantic love between parents and unconditional love for children. Not only that, but they have triggered warnings in terms of "the end of men" and "the end of sex". Journalists, film-makers, and novelists have exploited these worries to depict dystopic futures devoid of intimacy, individuality, and creativity.

In my talk, I explore the relation between love and uptake of reproductive technologies. Objections in terms of fractures in love, either parental or between partners, come from a variety of directions, from the conservative (Kass 2003) to the liberal (Gheaus 2014). I examine both claims (1) that the separation of procreation from sex and intimacy is a threat to love, and (2) that control over the traits of one's future offspring betrays inadequate parental love. I also problematize the temptation to turn towards medicine and genetics to fix problems that could be, and perhaps should be, more effectively addressed in less sophisticated ways. In so doing, I hope to reveal both the bias towards Sci-Fi solutions and the status quo bias against unavoidable progress – not only technical but also cultural, social and legal.

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Cassandra's kiss. About the certainty of the future and the uncertainty of the past

Devisch, Ignaas
Ignaas.Devisch@ugent.be

For quite some time now, numerous conferences are organized to predict how due to technology, we as human beings, will be modified in the future. Time and again, this future is called 'uncertain', be it as a threat, be it as an opportunity to solve all of our problems. Apparently, we know that for sure that the future will differ substantially from our times. Today, talking about ehealth or human enhancement, this also seems to be the case. Once again, our future will be reshaped substantially, and apparently, we know it for sure. Either utopia will become real or the apocalypse is awaiting us.

Analyzing this, one cannot but conclude that we were quite sure about the uncertainty of the future. Today, this might come to an end. For a long time, we could endlessly speculate about how to life when certain technologies would become true. As technology – whole genome sequencing, xeno-transplantation, nano-technology, big data – is already at work, we do no longer have to speculate about what might happen. We need to start from what happens as we speak. Therefore, the ethical question has shifted from 'how to avoid certain technologies to become real' to 'do we want to make use of what does exist already'?

In other words, as always ethics is too late. But philosophy might still save us, not from a dark future, but from the idea that we would need to be saved from something, i.c. a dark future. Lectures will be held on genome sequencing, privacy and sharing of data, philosophy and the fiction of science, etc. This *special session* consists of four short input talks (10 Min. each) and an open roundtable where the audience can participate.

Sport and Narrative Medicine

Edgar, Andrew
edgar@cardiff.ac.uk

Keywords: Medical Humanities; Suffering; Illness; Salutogenesis

Abstract: Participation in sport may be justified on the grounds that it contributes to the health, and thus physical and indeed mental wellbeing, of the participant. It may be argued that such a justification, while having merits, presupposes a narrowly biomedical model of health, where illness is the little more than dysfunctioning of a biological mechanism (and sport therefore sustains that mechanism's normal functioning). In contrast, approaches derived from the medical humanities and salutogenetic approaches may argue that health, illness and disease are constituted through the narratives within which the patient contextualises and gives meaning and coherence to their physical and mental conditions (see Frank 1995, Charon 2007). A patient

may yet live well and flourish despite suffering from illness and disability, if that condition can be meaningfully integrated into their lives. A crucial element of the treatment of (in particular chronic) health conditions thereby becomes the process of providing patients with appropriate cultural resources through which to make sense of their condition (Edgar 2007). It will be argued that participation in sport provides important hermeneutic resources, precisely because sport requires the player to confront their own physical (and mental) limitations, to endure pain and suffering, to cope with bad luck, and ultimately to make sense of the futility of losing. Within the comparative safety of the 'magic circle' of play, participation in sport allows the player to experience their own finitude and vulnerability (Edgar 2013). They are thereby encouraged to development of the sort of hermeneutic competences that would allow them, as a patient, to flourish, living a meaning life in the face of illness and suffering.

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The pathology and negativity of biological ageing

Ehni, Hans-Joerg
hans-joerg.ehni@uni-tuebingen.de

One of the basic assumptions of current gerontology is that normal ageing should be distinguished from pathological ageing. However, recent contributions from the biological science of ageing (biogerontology) argue that ageing should be categorized as a disease. Some biogerontologists have also pushed for classifying ageing as a disease in the forth-coming ICD-11. At the same time there are positive responses from the FDA signaling a general openness to an equation of ageing and disease. At the same time a thorough analysis of the arguments and the relation to the previous discussion of the topic in the theory of medicine is missing. This paper will provide an overview of the main arguments for and against the classification of ageing as a disease. While the rejection of this equation from prominent theories of health (Boorse, Nordenfelt) fails, the main arguments from a biogerontological perspective turn out to require further reflection. These arguments are that biological ageing causes age-related diseases and that the pathologies linked to biological ageing will lead to death once other causes of death will be eliminated. The first of these argument turns out to be problematic from a pragmatic medical perspective since classifying ageing as a disease while not provide any guidance for medical practice. The second argument leads to the question when and how to die since a death from old age was considered to be a good death from antiquity. As a esult of these reflections, the paper will argue that biological ageing despite of its pathogenic effects should not be considered a disease, but as an instance of physical evil. This will allow developing a broader more comprehensive strategy on how to deal with its negative aspects.

Shedding light on the Black Box

Ferretti, Agata; Blasimme, Alessandro; Schneider, Manuel; Vayena, Effy
agata.ferretti@hest.ethz.ch

Recent advances in artificial intelligence (AI) research led to an explosion of AI applications in a variety of fields including medicine. A commonly held view in this domain is that forms of

AI like machine learning and neural networks entail a so-called “Black Box”. Despite their capacity to efficiently automate some important decision-making processes (like pathological classification), these systems, so the argument goes, remain fundamentally opaque to human understanding. In other words, we can assess their performance, but we cannot explain how these machines actually do what they do. This type of information is buried inside AI systems and remains inaccessible even to the engineers that designed them. The actual functioning of AI systems is therefore bound to remain opaque, mysterious and unexplainable. This state of thing can jeopardize accountability and liability in medical practices, thus creating serious ethical and regulatory concerns.

This view does not seem well-supported by the actual functioning of AI systems. In this paper, we therefore set out to clarify the notion of opacity (black box) form a conceptual point of view. We first distinguish among three forms of opacity: (I) Concealment Opacity, (II) Epistemic Opacity – which in turn consists of (a) Procedural Unawareness and (b) Procedural Darkness – and (III) Explanatory Opacity. We then explain their sources, and suggest ways to remove or overcome each of them.

We then move on to illustrate the ethical and regulatory implications of our analysis in the medical field. From a normative perspective, we argue in favour of validation mechanisms to document AI accuracy, effectiveness, fairness, and that are able to reconstruct AI’s behaviour in case of mal functioning or undesired outcomes. The idea of “black-box” creates a halo of mystery around AI in general and casts major doubts regarding the possibility of effective regulations. Contrary to such tendencies, our paper lays conceptual groundwork for demystifying the notion of opacity, and paves the way for regulatory interventions based on a more realistic account of AI.

Let’s Talk About Sex… Doulas

Firth, Steve
shedlock2000@gmail.com

Whilst it is well understood that sex is an important part of the human condition, disabled persons often have difficulty engaging with that part of their humanity. This difficulty is often generated by physical impairments and the psychological issues which relate to an individual’s self identity. The aim of this presentation is to highlight the work of recently developed organisations which offer physiological relief to impaired persons through sex doulas.

Over the last 30 years, under-the-radar activities were arranged by inclusion organisations in the UK to assist disabled people with the sexual aspects of their lives. Government funding was never available for these initiatives and private funding proved difficult to obtain. Funding issues have since effectively terminated such activities. However, recently formed organisations (NPOs and NGOs) in North East Asia have been created to help disabled persons resolve their sexual needs and wants.

In line with many inclusion organisations, these NPOs and NGOs consider sexual release to be a part of everyday living (like brushing teeth and bathing) and hold that the enhancement of sexual life is a necessary condition for social independence. They argue that their services improve the quality of life, happiness, and self worth of disabled persons. By offering medically-focused services, they believe that they are well positioned to offer physical release (together with some measure of mental support) to disabled persons who are severally unable to engage in the sexual aspects of life.

The successes of the Eastern organisations invites us to look at our options in the West where our welfare states have been tasked to facilitate the greater inclusion of disabled persons into society. In this endeavour the welfare state has become obligated to supplying such services as prosthetics, chirping crosswalks, Braille Libraries, career training, cochlear implants, etc. Given that these services seek to advance a certain quality of life, and given that a sexual life is an important part of life-in-general, the question arises as to whether or not the welfare state should also be obligated to help assist certain disabled persons enhance their sexual lives. If we believe the welfare state *is* obligated to assist in this matter, then a number of ethical dilemmas arise: Is the provision of psychological relief from sexual tensions an appropriate response to the issue of unsated sexual tensions? Who might be eligible for such services? What should be the threshold of the financial burden? If it is appropriate for a welfare state to provide the services of sex doulas, under what circumstances is it appropriate? And if we believe the welfare state is *not* obligated to assist in this matter, then we are left owing the disabled person a very good explanation for why we do not value the quality of their lives as we do our own.

Still Alice? Ethical Aspects of Conceptualizing Selfhood in Dementia

Folkmarson Käll, Lisa; Zeiler, Kristin
lisa.kall@gender.su.se

The paper examines how early screening of dementia, and subsequent diagnosis, can come to function as a promise of continuous control of one's bodily self, and one's bodily future, despite loss of cognitive functions, through the mobilizing of social relations and networks, and through material-discursive performances of dementia-friendly environments. It examines how discourses about early screening and remaining abilities help shape specific understandings of *subjectivity*, about *what it means to live a good life with dementia,* and what it means to be *responsible*, as a subject, for oneself and one's close ones.

We ask what it might mean not to take responsibility for one's own continuation as a subject in a social and cultural context that prescribes or demands such responsibility in a specific way. While not denying the value of not conceptualizing the person with dementia solely in terms of loss or diminishment and instead focusing on remaining abilities throughout the condition, we argue that we need to problematize the very terms in which conceptions of loss and remaining abilities are articulated. The paper also offers a reading of the film *Still Alice* that approaches existential and ethical dilemmas involved in the experience of living with dementia to make this point.

Frankenstein, Bio-enhancement, and Particular Cases. How Narrative Can Shed Light on Bioethical Thinking

Galletti, Matteo
matteo.galletti@unifi.it

Traditionally Mary Shelley's Frankenstein has been a very invaluable novel in thinking about the ethical limits and potentialities of life sciences. As Jon Turney has shown in his book *Frankenstein's Footsteps* (1998), the Frankenstein's creature symbolized the long history of fears and hopes associated to the development of biological science, even in the popular culture. Shelley's novel can still be a very treasure trove for those who are interested in understanding the social and ethical issues in the new frontiers of genetics.

Recently Eileen Hunt Botting gave an innovative reading of the novel as a series of counterfactual though experiments aimed at clarifying important issues in children's rights. For Botting Frankenstein is a philosophical treatise in guise of a novel that deals with five questions about: the parental responsibility toward a child born thanks to the scientific aid and without a biological mother; the elicited psychological, emotional, and social consequences when a parent abandons a child because of fear and disgust of the child's hideous form; the future of a child that could survive on her own without the provision of fundamental rights to warmth, food, water, education, etc.; the societal responsibility toward the child to not hurt or abuse her; the right of every child to share love. Each issue is introduced by a counterfactual question: What if…?

In a few pages, Botting employs Shelley's narrative to focus on post-human child's status. What if genetic technologies would allow us to create genetically modified children, endowed with enhanced capacities? I will argue that this kind of narrative analysis is very fruitful to frame and discuss bioethical issues in biological enhancement, because it permits to build an analytic framework to give a case-by-case assessment. In particular, the right to share love Botting introduces is a key concept to morally evaluate not the "enhancement" per se, but particular situations where parents intentionally decide to recourse to enhancing biotechnologies.

Old ideas from a new philosophical model: levels and means of human life extension

García-Barranquero, Pablo
pablogarcia@uma.es

Since 2000, the possibility of extending human lifespan has been a highly debated topic by both biomedical scientists (de Grey and Rae, 2007; Olshansky & Carnes, 2002) and philosophers (Agar, 2010; Overall, 2003). One kind of attempt to find middle ground in this debate has been efforts to distinguish two kinds of life extension: moderate and radical (Agar, 2013; Glannon 2002; Lucke et al, 2006). Although, there are three reasons for rejecting this distinction:

1. The difference between moderate and radical life extension cannot be explained only by a quantitative measurement but also by a qualitative distinction. Jeanne Calment's age is not a maximum lifespan (imaginable) and I propose the concept of Uncertainty Threshold of Longevity to debate whether there is a limit in our species.
2. The question of whether a therapy will be considered in a Weak Sense or in a Strong Sense. It still does not exist, save (or with the exception of) caloric restriction, many promising researches on aging. How to evaluate whether a treatment will add more years or more health or how to know the best way to live 200 years?
3. A thought experiment named Peter Pan Drug suggests that a healthspan extension, in a radical sense, allows us to re-think about a lifestyle totally different from now. Example: a life extended to 120 years but maintaining physical and mental condition all the time, is it moderate kind?

I propose an alternative model for resolving this debate. This model builds upon the distinctions that Juengst (et al, 2003) and Wareham (2016) make about different levels and means to control human senescence, to propose the following conceptual categories: (a) Compression of Morbidity; (b) Slowed Aging; (c) Negligible Aging or SENS; (d) Arrested Aging; (e) Escaping Aging. In addition, I have to add several concepts which are relevant for my purpose: indefinite life, virtual sort of immortality or (true) immortality.

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Experiences of knowledge mobilization for decision making among and towards oncological patients and their non-professional caregivers (binomial) in Mexico

Garcia-Miranda, Rosario
rgmiranda7@gmail.com

Introduction: The social aspects of the patient and their family environment are increasingly considered in strategies to overcome cancer without impairing their quality of life. However, little is known about their experiences in the processes and mechanisms of knowledge mobilization to perform their care work, particularly in Mexico

Objectives: Identify the knowledge needs of the binomials (oncology patients and their non-professional caregivers), where they obtain their knowledge and how do they mobilize it to carry out the work of care.

Methods: During 2016 and 2017, an exploratory study, mixed methods, was conducted in Mexico. Fourteen in-depth interviews with binomials, participant observations in two face-to-face and two online mutual help groups, 97 semi-structured interviews with medical staff from three hospitals and online interviews with academic experts on this field.

Results: There were few coincidences between the knowledge mobilization strategies reported as successful by the binomials and those described by the medical staff and academic experts. Among others, two very important aspects were identified: invisibility of non-professional caregivers by medical personnel and the importance and relevance of the use of online networks and internet regardless of socioeconomic characteristics

Conclusions: Current policies regarding care and accompaniment to non-professional caregivers of oncological patients do not incorporate neither in their design nor in their implementation the strategies and processes of knowledge mobilization reported as feasible and successful. It is needed to know the opinions and experiences of all actors involved if we want to improve their wellbeing.

The future of biobanks: hypes, hopes and uncertainties

Gefenas, Eugenijus; Lekstutiene Jurate
eugenijus.gefenas@mf.vu.lt

Hyping different biomedical technologies can very well lead to a loss of public trust and public support for them. This happens when promises to bring health care benefits related to these technologies generate public expectation, which are not fulfilled within an expected timeframe. Therefore, avoiding such a "hyping scenario" seems to be very important for the sustainable development of new biomedical technologies and is particularly relevant for biobanks. The reason is that public trust and support is vital to ensure collection of biological materials and related personal data, which is necessary condition for a successful functioning of biobanks. However, an overview of recent developments in the biobanking field has revealed some important challenges to the future developments of biobanks. The metaphor of "biobank bubble burst" was used to convey the idea of unfulfilled promises (Chalmers et al, 2016). It has been noted, for example, that although biobanks have attracted considerable investment over the past twenty years, they did not realize the promised expectations to reduce the time and costs of research by providing ready access to large numbers of samples and data. In some countries support for biobanking has already been reduced and funding withdrawn. This paper aims to analyze the major challenges and ethical concerns related to the future developments of biobanks.

Solidarity in dementia care: a lesson of art

Głos, Aleksandra
olaglos@gmail.com

Dementia is a challenge for contemporary healthcare. And it is a threefold one: financial, structural, and philosophical. The spread and nature of this disease make it an impossible burden for traditional healthcare, and its global costs are gigantic. However, the philosophical challenge is crucial. Dementia blurs the image of human nature and human capacities. Not only does it lead to deterioration of mental capacity, but also, paradoxically, by destroying higher cognitive functions, it teaches us a lesson about the extensive potential of the human psyche. One of the most touching presentations of this endless potential is *I remember better when I paint*, a film that shows how artistic creation and an emotionally friendly environment can improve the highly cognitive, left-hemisphere brain functions. The memorable sentence 'I remember better when I paint' is not only a homage paid to art, but also a fascinating challenge to the idealized Kantian vision of human mental capacities prevalent in the European tradition, as well as the Olympic demands of the rational choice theory popular in Anglo-American culture. Dementia therefore not only dissociates the human mind but also enriches its picture, revealing its yet-unexamined and beautifully surprising nature. A consequence of this expansion is a broadening of the concept of human identity and, more practically, autonomy, which in the case of dementia patients is called a 'relational' one. The idea of a 'relational' autonomy sounds quite paradoxical. Nonetheless, in order to remain 'autonomous,' people suffering from dementia need the support of others/those that are able to understand their will, in spite of the often limited ability to express it. As such, dementia shows a distorted, but at the same time a clearer image of the extent to which humans depend on others.

Therefore, the lesson of art discussed in the paper will be a twofold one. Firstly, I will present the salutary influence artistic activities have on dementia patients, their well-being, and most fascinatingly, their cognitive capacities (not to forget their relations with their loved ones, as in the case of a woman with severe dementia taken out dancing every month by her husband as it was a lifelong habit for them; this allowed them to sustain their relation despite her very limited cognitive capacity). Secondly, I will discuss the irreplaceable lesson the art made by dementia patients gives to all dementia carers and researchers. This is the lesson on the meanders of the human condition and the beauty of human solidarity.

Narrating Decreased Sound Tolerance in Literature

Glotova, Elena
elena.glotova@umu.se

The talk aims to present, conciliate and systematize a variety of modes of expression of decreased sound tolerance (DST) in classical literature, genre fiction, and autopathographic narratives, and lies at the intersection of medicine and literature.

First, it contextualizes DST in contemporary clinical studies and previous scholarship. Originally discussed in the audiology literature and partially contextualized within the nineteenth-century theory of psychopathological disorders, decreased sound tolerance is currently subdivided into hyperacusis and misophonia. Both subgroups can be highly interconnected, and are characterized by enhanced physiological reaction and high emotional response that results from intolerance to specific auditory stimuli (Jastreboff and Jastreboff 2002). Hyperacusis presupposes response to sound above a certain intensity, whereas misophonia (only discovered in 2000s) is a strong dislike of certain sounds, accompanied by distressing, unusually intense emotional reactions, behavior responses of confrontation and avoidance, and feelings of alienation and shame (Taylor 2017). To date, misophonia has not been formally recognized in any of the contemporary psychiatric classification systems and has received little attention from psychiatric researchers, let alone in literary scholarship. At the same time, a growing number of fiction and non-fiction contemporary narratives address disproportional sound sensitivity, where the characters present their self-knowledge, concerns and coping strategies through their narratives of disorder.

Second, the presentation addresses the early accounts of DST in the 19-th century horror fiction. By using the example of Edgar Allan Poe’s short story *The Tell-Tale Heart* (1843) it intends to explore the nature of the protagonist’s mental instability in connection with physiological symptoms of disproportional sound sensitivity. The talk will proceed to the representations of hyperacusis and misophonia in the 20th century fantasy short stories to show the way J.G. Ballard and John Steinbeck addressed the anxiety over emerging technology and noise producing objects.

An overview of contemporary published works on sound-sensitivity and misophonia will finalize the talk. Here, recent published young adult novels and autopathographic narratives, or autopathographies (Aronson 2000) allow to explore the significance of decreased sound tolerance for character construction, and analyze how misophonia can perform as a channel for audience identification with the protagonists, and communication of experience of living with the condition.

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The robots are coming: social and ethical issues

Gunson, Darryl
Darryl.Gunson@uws.ac.uk

Bioethicists have long been interested in the role that new technology may play in our lives. This has, of course, included extensive discussion of core biomedical topics such as reproductive technologies and genetics, and other biomedical developments. However, bioethical interests need not be restricted to such things – what has been called the ‘northern agenda’. A rather more expansive understanding of the ‘bios’ of bioethics allows us to see that our interest in technology need not be restricted to exemplars of medical bioscience, but extends to areas of life – bios – not normally discussed.

It is in this context that developments in robotics are a fit topic for bioethical discussion, particularly as there has been much recent speculation as to the roles that new robots might play in our lives. This paper discusses some general questions that any ethical discussion of robots prompts. It also discusses some specific examples, such as sex robots.

More specifically the paper discusses:

Are they ours to use as we wish? The answer to this will depend on whether we regard robots as persons or not. If they are not so regarded then we are free, subject to legal and moral restrictions, to do with them what we like. They are a piece of technology.

If the answer to the question of personhood is disputed, then this will reopen longstanding debates of what it is that qualifies any being as a moral agent: what are the necessary and sufficient conditions?

Even if we think there are no restrictions grounded in the kind of thing that robots are, what kinds of things can we use them for? And, what restrictions should there be? Examples discussed include: Work; war; Science; Care; Sex.

The example of sex is pursued in more depth. One contention is that using robots for some forms of sex, such as rape scenarios, although highly controversial, is not objectionable on purely consequentialist grounds. Just as is the case with the connection between violent computer games and actual violence, there is little evidence that allowing individuals to indulge rape fantasies with robots will increase the rates of actual rape. Alternative reasons as to why such cases may be unethical are also discussed.

The paper concludes with the view that the topic of robots reopens many discussions that have long been central to bioethical enquiry, and reveals that, just as in past cases, there are no easy answers.

Uterine Imaginaries. A Narrative Exploration of Living Without and Hoping for a Uterus.

Guntram, Lisa
Lisa.guntram@liu.se

Two years ago, a doctor involved in the Swedish uterus transplantation trial told me the following story. When attending an international conference, the team had invited one of the women who had received a uterus and her partner to talk about their experience of the trial. But when the medical team described the purpose of their procedure something unexpected happened.

We [the medical professionals] sat there and said: ‘The purpose of this transplantation is of course to have a healthy baby, and we are not there yet’.

And then the father said: ‘Wait a minute…I can’t agree with you on that’.

And then you thought ‘Oh, what’s gonna happen now?’

And then he said: ‘No, this is the first time ever that we have been like any other couple trying to get pregnant. We’ve never been that way before. This makes us…We are feeling really good. If this doesn’t work, if she doesn’t get pregnant, then we have another plan. So I can’t agree that *that* [to have a healthy child] is the only purpose – right now we are feeling very good.’

And I dropped my chin. I think that we all did, in our academic…

We just sat there and thought – I almost get chills when I talk about it …

I thought ‘So wise! He’s completely right!’

While we are so focused on results, on the healthy child … because if we don’t get a child… in some way, it will mean that the project failed.

When listening to the story I was struck by the surprise expressed. How come, I wondered, did the lived experience of the patient’s partner seem so obscured from the orientation of the physician?

In this paper, I address this question through a reading of narratives offered by some the 200 000 women in Europe living with uterine factor infertility and who thus is considered to be in need of uterus transplantation. Specifically, I explore how past experiences of living without a uterus, along with hopes of a future with a uterus, shape meanings and expectations accorded to uterus transplantation. What may this innovation – situated in a particular context and targeting individuals with specific histories and hopes – enable subjects to *do* or *become*? And what meanings and values are assigned to the procedure by those involved in "using" it? In conclusion, I show how my narrative exploration shed new light on what uterus transplantation might *do*, beyond producing parents and children (c.f. Thompson, 2005). This also allows for a discussion of how a narrative analysis of the lived experiences of uterine factor infertility can unpack the affordances of uterus transplantation (see e.g. Abrishami et al., 2014).

Forensic therapeutic measures for older individuals in Austria and Switzerland

Haesen S, Merkt H, Imber A, Wangmo T, Elger B
sophie.haesen@unibas.ch

In many Western societies, prisoners constitute a group that is isolated from the rest of the population, and living in most cases, in a total institution. However, an important goal of imprisonment is eventual reintegration which may be hard to realize for the growing population of older prisoners. For older prisoners with mental health problems, this goal might even be harder to reach. In many penal codes, therapeutic measures have been introduced to facilitate successful resocialisation of offenders with psychiatric disorders, but the open-ended nature of these measures can pose problems especially for older individuals. Successful implementation of these measures depends on various factors that are not always purely legal in nature. Distribution of tasks between federal states needs critical but constructive interactions among various stakeholders at all levels.

Austria and Switzerland are neighboring states with comparable population and prison population size. Both countries are federal republics with varying tasks delegated to its states (the Swiss "Kantone" or the Austrian "Bundesländer"). The Swiss penal code has been revised in 2007, introducing therapeutic institutional measures or indefinite incarceration. This was in part influenced by the public reaction to media coverage of several high-profile crimes. The Austrian penal system was revised in 2015, and important structural changes to the forensic treatment possibilities have been made. In this case as well, the public reaction to media coverage of prison conditions may have played a part.

Both Switzerland and Austria have signed several international and European regulations, for example the European Convention on Human Rights, the CoE's disability strategy or the UN Convention on the Rights of Persons with Disabilities (CRPD), which need to be applied to the Swiss and Austrian context to see if the two states' regulations comply with these international regulations.

The legal settings between Switzerland and Austria regarding therapeutic measures differ significantly. Within Switzerland, responsibility for prisoner healthcare and also for execution of institutional therapeutic measures lies with the department of justice or the department of health depending on the canton. This in turn may influence dual loyalty concerns on the part of the treating physicians. Another problem is that although the penal law is valid for the entire nation, its execution is delegated to the cantons. This may lead to differences in its application due to budgetary and logistical conditions, as all cantons do not have equal resources.

In Austria, the national law has been centralized and is being executed on the national level; responsibility lies with the department of justice. In 2015, extensive changes to the existing laws were proposed by a special committee. Some of these changes have already been implemented and might be useful in the Swiss context.

What is in a Name? Everything! Science, Suffering and the Validation of Illness.

Hall, Katherine
katherine.hall@otago.ac.nz

What does a valid illness mean? Who determines this and how? What does being told you have an invalid illness mean for those designated thus? How does the Medical Humanities help with these questions?

This paper will argue that understanding what illness validity is, and how this is determined, is not some idle intellectual exercise but literally a matter of life and death: many patients have succumbed, not to the effects of their illness, but to the social responses of shame and scapegoating, stigmatisation and marginalisation, all due to the consequences of having had their illness labelled 'invalid'. The determinants of illness validity are not purely scientific or objective, nor are they defined solely by the medical community, but are a complex amalgam of societal and subjective forces.

I will illustrate these points by drawing on my empirical research with people suffering from myalgic encephalitis or chronic fatigue syndrome. This illness is highly contested in terms of its validity, and people who suffer from it are not only living on the liminal edges of medicine but also frequently on the liminal edges of society as well. They exist in the unenviable state of 'Un-wellness within Health' (to cast it as the antithesis of Carel's concept of 'Health within Illness').[i] They endure epistemic injustice, and testimonial injustice[ii]. They suffer, not by being patients, but by being un-patients.

Philosophy can do much to challenge and unpack assumptions and arguments about the validity, or not, of an illness. Sometimes, however, philosophy is not the most accessible of languages for others to access and employ! This is where the humanities can enter the conversation and provide the means and modalities by which the discussion is deepened, broadened and illuminated. This allows connections to be made, both in reasoning and in relationships. With these connections, a deeper understanding of illness validity can be reached, to the mutual benefit of all concerned.

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[i] Carel, Havi. *Phenomenology of Illness*. 2016. Oxford University Press, Oxford.

[ii] Fricker, Miranda. Epistemic Injustice. Power and the Ethics of Knowing. 2007. Oxford University Press, Oxford.

Narrative meaning making and integration of falling ill: Reconstruction of Life Events (RE-LIFE)

Hartog, Iris D; Oreel, Tom H; Scherer-Rath, Michael; Netjes, Justine E; Henriques, José P S; van Laarhoven, Hanneke W M; Sprangers, Mirjam A G; Nieuwkerk, Pythia T
i.d.hartog@amc.uva.nl

Falling seriously ill may conflict with peoples' goals and expectations, triggering existential questions about the cause of the event and the meaning for one's life. In psychology and (health) sociology, research has been performed on the way people restore meaning and adapt to their new situation after stressful life events, influencing the quality of life they experience.

Combining theories of contingency and narrative identity, we propose a humanities approach, emphasizing the crisis of meaning people may experience when confronted with the 'randomness of life', which requires narrative reconstruction. Following the philosopher Kurt Wuchterl, falling ill is considered a *contingent* life event: something that befalls people but could also have been otherwise. The word contingent means 'something that is neither necessary nor impossible', referring to the idea that everything, including one's own life, could have been different.

If falling seriously ill conflicts with people's ultimate life goals and worldview, it may lead to a so-called 'experience of contingency': a crisis of meaning, caused by the disruption of the person's life narrative. Trying to make sense of such events, people may engage in a process of narrative meaning making: configuring separate events into a meaningful whole. Eventually, this may lead to integration of the event in the life story to a greater or lesser extent, changing peoples' life narrative and consequently their narrative identity.

We distinguish between four 'modes' of narrative integration: 1) denying, in which the contingency and/or existential relevance of the event is ignored or reasoned away; 2) acknowledging, in which the contingency and existential relevance of the event are acknowledged; 3) accepting, in which the new reality that comes with the consequences is accepted and the event is re-interpreted; 4) receiving, in which new possibilities are embraced and the integration of the event in the life narrative is completed. In this mode the event is given a meaningful place without disregarding its contingency and disruptive meaning.

To enable the empirical testing of the theoretical model described above, the Reconstruction of Life Events (RE-LIFE) Questionnaire was developed operationalizing the concepts worldview, ultimate life goals, experience of contingency, narrative meaning making, narrative integration and quality of life. The questionnaire was completed by 249 cardiac patients, three and six months after revascularization.

Classical test theory and factor analyses were used to analyze its psychometric characteristics. The following theoretical distinctions were confirmed: 'Influence of life event on ultimate life goals', 'Importance of ultimate life goals' and 'Experience of contingency'. For 'Worldview', the sub-concepts 'absolute immanence' and 'transcendence' were found. For 'Narrative integration', we found three 'modes' instead of the hypothesized four. The questions related to 'Narrative meaning making' need further examination.

At the conference, the results will be presented with respect to the theoretical distinctions and the hypothesized relationships among the concepts and with criterion measures such as health-related quality of life.

Dependent on these results, the RE-LIFE Questionnaire may be used in research to improve our understanding of the relationships among worldview, ultimate life goals, and narrative meaning making and integration of life events.

Man Machine – Machine Man. The question of humanity at the intersection of biology and technology

Häyry, Matti
matti.hayry@aalto.fi

How many mechanical spare parts can we install into human beings before they stop being human – or stop being considered human? Have fighter pilots, connected as they are to the controls of their plane, already crossed the line? What about today's cyber citizens, who spend large parts of their lives in the internet?

Conversely, how many human-like parts can we install into machines before they stop being machines – or stop being considered machines? Have care robots, capable as they are of interaction and caring behaviour, already crossed the line? What about self-learning computers that are invisibly creating realities of their own?

These questions face us more and more intensely with advances in technology and biotechnology. What does it mean to be a human being? What does it mean to be human? Who can have rights or duties? What can have rights or duties?

This presentation approaches questions like these by delineating two possible paths of development. The first starts with an indisputably human being (the author) and ends up in a silicon copy of him, which nevertheless seems to have a strong claim for the moral status (whatever that is) that the community of humans now assigns to the original being. The second

starts with innocuous household appliances and ends up in a version of a human being (the author) produced by synthetic biology, the status of which remains ambiguous.
The presentation uses philosophical distinctions, discussions in internet forums, and science fiction examples to complete a case for the baffling nature of questions of humanity at the intersection of biology and technology.

Health, dis-ease, illness and understanding sickness: facts, complexity, results and outcomes of some human interventions.

Henriques, Augusto J
henriques.augusto.ost@gmail.com

Using a retrospective view in terms of "*health narratives and some apparent fabrication of truth*", the gathering of unbiased information, shows that not all is that simple and straight forwards. With a simple attempt to promote a careful up-to-date reflection, data collection gathered for some years, shows a vast number of issues that one may realize not all in the vast field of health, health care and dis-ease treatment is/it has been so simple and well. Health promotion and dis-ease prevention, its treatment, and the understanding of sickness, it is an issue that has been looked under various prisms and paradigms throughout times. For decades, (seen as unbiased), studies and research conducted in Europe, America and elsewhere, show and raise situations that deserve a careful evaluation and appraisal. Though, the general health of the population on the last decades has improved, as well its longevity, reality is often related to issues deserving proper attention, a continuum careful appraisal, reflection and subsequent unbiased actions. With longevity, the social system, has to answer to many and varied problems, in order to prevent poor outcomes. For so much, a gathering of quantitative and qualitative data, shows that not all is that simple. Interpretation of facts, that have and are occurring throughout the last decades and end of last century, may in reality become controversial. Expectations, often point to disasters if nothing is done to prevent, by properly informing and empowering patients, the individual citizen and professionals of and for their own actions and possible defficiencies. An attempt, to a priori create the right answers, rather than awaiting for dis-ease situations to develop, can be a viable solution. Numbers show that the lower the mortality, the higher the morbidity. Many measures, disciplines and philosophical proposals based on solid scientific backgrounds may contribute to advance health-care. Autonomous and independent system of diagnosis and treatment that promote health, to minimize dis-ease, illness and understand sickness, may contribute to problems resolution, having in mind the relief, treatment and cure of structural and functional problems of the human being, including the mental and emotional state of the individual patient, in order to reach the ideal (individual) state of Total Health and Well Being, may be a major step forwards. Not, the sole intention, to treat specific diseases and symptoms, as often, there is no single specific treatment for a specific situation. Individuals', possible independent care, education, promotion and health capacitation, treatment and prevention (including primary, secondary, tertiary and primordial) of dis-eases may be a priority. Treatment methods characterized by respecting and being in total 'bio-logical' harmony with the individual, (biological) function and structural (anatomical) aspects of the person, seen as an all time (sole) individual, taking into account the organization and constitution of the organism, and its correlation with the environment, may be a(nother) possible more accurate (in the long term, cheaper) solution.

Avoiding cognitive biases in the assessment of emerging technologies

Hofmman, Bjorn
bjorn.hofmann@medisin.uio.no

While there is evidence that technological breakthroughs are more difficult to get (Betz 2018), technologies, such as gene editing, show great promise on a wide range of fields. These technologies may also alter humans in more constitutive and speedy ways than before. Assessments and decisions on new technologies tend to be influenced by ethical conception delay and by various cognitive biases. By exploring a range of cognitive biases, Hofmann will explore how philosophy of medicine can contribute to a more rational assessment and debate on emergent technologies

Research misconduct in the philosophy of medicine – a (series of) category mistake(s)?

Holm, Søren
soren.holm@manchester.ac.uk

This paper provides an analysis of how the concept of 'research misconduct' applies to the production of work in theoretical disciplines like the philosophy of medicine and medical ethics. The first part provides a quick overview of the types of misconduct where identical or closely analoguous forms of actions/behaviour can be found in the empirical sciences and in philosophical work, e.g. plagiarism, authorship misconduct, or misrepresentation of prior work. The second, larger and hopefully more interesting part will then discuss whether well-known categories of misconduct in the empirical sciences such as fabrication, falsification and manipulation of data; or deliberate breach of research ethics have any application to theoretical work. It will be argued that whereas the individual, standard categories of misconduct have no direct application to theoretical work, the underlying and more basic concept of deliberate deception has. The task then becomes to analyse and define the characteristics of, and wrong making features inherent in deliberate, philosophical deception. The analysis will show that we can define and identify misconduct if philosophical work in the philosophy of medicine and medical ethics is characterised as making a particular epistemological claim, i.e. that the arguments presented provide full or partial justification for the stated conclusions given the set of explicitly stated assumptions and a set of standard implicit assumptions. Misconduct can then be defined as knowingly and deliberately claiming to have justified conclusions, for which the work does not in reality provide sufficient warrant. Some examples of philosophical misconduct will also be presented.

Medical Detective Stories: A Case of Dr. Thorndyke

Jajszczok, Justyna
jajszczok.justyna@gmail.com

Physician writers tend to use their professional experience in their creative writing: for instance, Mikhail Bulgakov based his collection of short stories *A Young Doctor's Notebook* (1925-26) on cases from his practice, while William Carlos Williams' poems, such as "From a Window" (1940) or "The Birth" (1957) reflect the parallels between his literary career and that of a paediatrician and obstetrician. Perhaps the most famous doctor-writer of the Victorian and Edwardian period was Arthur Conan Doyle (1859-1930), the creator of Sherlock Holmes. Doyle based his detective on a real-life physician and his university mentor, Joseph Bell, and had another physician – this time fictitious – Dr John Watson narrate his stories.

Regardless of the background of its author or narrator, a detective story is closely related to a medical narrative in its very structure: both are stories of discovery and diagnosis; both, through identification of the pathogenic agent, offer solutions and remedies; both strive to contain and eliminate the source of the problem. These analogies were of vital importance in Doyle's times, when themes employed by popular literature related to political tensions and scientific discoveries.

The final decades of the nineteenth century and the first of the twentieth century witnessed a number of developments in medical sciences: it was the so-called golden age of bacteriology, during which many infective agents of diseases were discovered; and disciplines such as tropical medicine and parasitology were established. At the same time, the period between the Franco-Prussian War and WWI was characterised by national unrest revolving around fears of foreign invasions, which were fuelled by alarmist messages of popular literature. Novels such as Richard Marsh's *The Beetle* (1897), Bram Stoker's *Dracula* (1897) and Guy Boothby's *Pharos the Egyptian* (1899) presented visions of foreign invaders whose exotic, supernatural powers threatened the very existence of civilised nations.

The aforementioned Arthur Conan Doyle is the most famous but by no means the only physician writer of detective stories who found their place in the overlap between medical, political, and literary influences. In my paper, I would like to present another one: R. Austin Freeman (1862-1943), the creator of Dr Thorndyke, a medical jurist. Drawing from his medical and colonial experience, Freeman created his own detective narratives, which included state-of-the-art medical and scientific knowledge, and at the same time propagated his conservative agenda. The aim of my paper is to show, through an analysis of selected Thorndyke stories, how and to what extent Freeman's medical background permeated his work, not just when it comes to thematic choices but mostly in terms of narrative structuring, especially with regard to the identification and containment of the pathogenic agents.

Arts and cultural activities for health and wellbeing: A Danish culture on prescription programme

Jensen, Anita
anita@hum.aau.dk

Cultural vitamins is a 'culture on prescription' programme delivered by a local authority in the North of Denmark running as a three-year pilot project. The programme is a ten-week programme for referred participants (groups of 8-12 individuals) who are on sick-leave with stress, anxiety or mild depression. The programme offers different engaging arts and cultural activities including choral singing, reading literature, museum/archive visits, theatre etc. This presentation will focus on the outcomes of program with focus on the mental, social and physical health of the participants, as well as the participants' preferences in art activities.

"Wellness Genomics" Research, Prevention, and Medical Meliorism: A Core Challenge for Ongoing International Efforts to Govern Human Gene Editing Research.

Juengst, Eric
ejuengst@med.unc.edu

Much human genome research to date focuses on identifying DNA sequence variants associated with pathological or risk-conferring phenotypes in order to improve diagnostic precision and individualized health risk forcasting. As human gene editing research advances, the hope is that these deleterious variants will become "medically actionable variants" that might be modified or replaced in the name of the health care. But why limit ourselves to seeking and editing out deleterious genomic variants, when the same tools could also help identify --and edit in-- variants associated with phenotypes at the high end of our species functional range? In fact, there is also rising scientific interest in "wellness genomics" research, aiming to identify genomic variants associated with positive traits, in order to better understand human biology when everything is working well. This means that medicine and society might soon face an interesting conundrum: once we discover which variants are associated with especially

advantageous traits and develop the means to provide them, why not offer patients the best available genomic options, even if they fall beyond what is typical for our species?
From one perspective, taking people beyond the normal range of functionality seems like the very definition of "genetic enhancement," which science policy bodies around the world continue to eschew as a morally problematic use of human gene editing techniques. On the other hand, enabling individuals to acquire "elite controller" status against HIV infection through gene editing seems very much like the moral equivalent of developing a HIV vaccine. In fact, some recommendations for governing human gene editing research, like the 2017 U.S. report *Human Gene Editing: Ethical and Social Implications,* already clear the way for gene editing research aimed at improving on normality in the name of prevention. Although that report continues to endorse a conventional proscriptive line against gene editing research aimed at "improving form and function beyond health…." it includes "strengthening the body to resist disease" on the acceptable side of that line, as a medically appropriate form of prevention. Presumably, this would legitimize any research aimed at editing in genomic variants associated with phenotypes at the desirable extreme of every health-related function, like superlative immune response, outlier tissue regeneration capacities or world-class tolerance for environmental toxins, as long as they were understood to be even more protective against disease than their more common "normal" counterparts. The same melioristic logic would also apply to alleles associated with unusually acute sensory abilities, intellectual genius, prolongevity, and champion levels of strength and endurance, as long as these phenotypes can be shown to afford even better health protections than the normal versions of these traits. In this way, wellness genomics research will create a conceptual soft spot in current thinking about the limits of gene editing research which will be increasingly important to clarify and reconstruct as this science matures around the globe.

Medical ethics education in Poland

Kaczmarek, Emilia
emilia.kaczmarek@uw.edu.pl

Courses of medical ethics are held at every medical university in Poland. Does it mean that polish medical students are well prepared to become decent or virtuous physicians?
Academic debate on the rationale for bioethical education, its objectives and efficacy has continued for years. The key questions for this debate are: Can ethics be taught? Do we really need to teach ethics to future physicians? What are the goals of bioethical education? Which didactic methods are optimal in teaching this subject? The purpose of the presentation is to briefly summarize the state of debate on ethical education and, most of all, confront it with actual data about courses of medical ethics for future health professionals in Poland.
During the presentation the results of systematic review of medical ethics syllabi from Polish faculties of medicine will be analysed. The data will show who teaches medical ethics; what is declared to be taught; what can be found on the reading lists and what methods of teaching are used.

Reconsidering the doctrine of genetic exceptionalism

Kakuk, Péter
kakuk.peter@sph.unideb.hu

The question of genetic exceptionalism appeared as a fundamental issue in the ethical controversies produced by the rapid advancement of genetic technologies and situated at the intersection of bioethics and public policy. As the Human Genome Project (HGP) was started, and a certain amount of the project has been assigned to the ethical, legal and social implications (ELSI) program, the academic literature intensively discussed the potential abuses of new DNA technologies. Insurance and employment served as a primary context for deliberations regarding the potential abuses of genetic information. Academics, health-advocacy groups, and lawmakers concerned that genetic information may be used by insurers to deny, limit or cancel health insurance. They also feared that some employers might only employ or retain individuals who are not pre-disposed to future disease onset, since healthy individuals are more productive. Originally genetic exceptionalism was defined as the widely held conviction in policy approaches that urges to provide special protections for the access and use of genetic information and treats genetic information as different from medical information. These policies usually refer to the privacy interests of individuals regarding their personal genetic information and the potential for genetic discrimination of individuals or groups based on their genetic information.

Genetic exceptionalism as a term was coined by Thomas Murray who - as a chair of the Task Force on Genetic Information and Insurance of the NIH-DOE Joint Working Group on the Ethical, Legal, and Social Implications of the Human Genome Project – used it to describe the claim that genetic information is sufficiently different from other kinds of health-related information that it deserves special protection or other exceptional measures. The term exceptionalism is borrowed from the earlier policy approach called HIV exceptionalism that insisted on treating HIV as a unique and discrete issue, segregated from other human diseases because of its special social and biological characteristics.

It is hardly questionable, that genetic exceptionalism dramatically influenced policy efforts on all levels that resulted in numerous laws, codes and guidelines adopting the exceptionalist stance on the regulatory issues of genetic information in the previous decades. However, some factors like the advancement of our genetic knowledge, the routinisation of genetics in everyday medical practice, the emergence of more robust empirical data on the usages of genetic information, and the transformation of our social and political attitudes toward the applications of genetic technologies, will certainly foster the reassessment of our genetic exceptionalist attitudes and policies in the future. The presentation reconsiders this two decade old bioethical controversy from our current perspective with questioning our ability to envision the ethical issues emerging from techno-scientific developments.

(Re)Humanizing modernity – Toulmin's vision of the ethics/science/society complex

Kakuk, Péter
kakuk.peter@sph.unideb.hu

There are not so many philosophers whose intellectual impact on the field of philosophy of medicine could be compared to that of Stephen Edelston Toulmin. As a special consultant, he worked for years with the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research that prepared the highly influential research ethics guideline, *the Belmont Report (1978)*. During this period, he collaborated with a member of the commission, Albert R. Jonsen in writing *The Abuse of Casuistry: A History of Moral Reasoning (1988)* that had a significant impact on the emerging field of bioethics and especially on practices of medical ethics education and training. In one of his last significant book project - *Cosmopolis: The Hidden Agenda of Modernity (1990)* – he attempts to set out the philosophical framework for a new cultural/political program for humanity in the age of globalization and techno sciences. Toulmin's vision finds support both in his earlier criticism placed on modern philosopher's „quest for certainty", and also - with a detailed discussion regarding our humanist traditions that existed before and without the universalist agenda of rationalism - he criticizes the standard representation of modernity and humanism. This paper attempts to consider the various ways that Toulmin conceptualized the relationship between ethics, science and society in his works from the perspective of his later „quest for humanizing modernity".

"The Philosophy of Wounds": Competing Philosophies of Pain in nineteenth-century Military Surgery

Kennaway, James
james.kennaway@roehampton.ac.uk

This paper will address a medical situation in which the human condition is framed in the most extreme terms – military surgery. It will argue that the nineteenth century saw contradictory developments in attitudes towards the brutal business of battlefield surgery and amputations. On the one hand, a humanitarian and even pacifist tendency can be seen, for instance in the public interest in the pathos of the scene and in the (gradual and patchy) supply of anaesthetics at the front. These trends were of course reflected in the creation of the Red Cross from the 1860s. At the same time, a veritable cult of masculine stoical endurance persisted and, in some ways, flourished. Manhood was to be judged by the capacity to endure pain. Often this cult was explicitly racialised, with ongoing scientific debates about which ethnic groups were most sensitive to pain and which best able to withstand it. In the context of imperialism, the supposedly superior powers of endurance of European troops were used to justify white rule, whereas examples of uncomplaining non-European troops under the knife were ascribed to physiological differences. In the twentieth century, the political dimensions of such thinking became more explicit, reaching an apogee in the work of Ernst Juenger, especially his 1934 essay *On Pain.* This paper will thus consider these competing conceptions of surgical pain, one Utilitarian-humanitarian and the other militaristic-sublime, to get to grips with what Thomas de Quincy called the "philosophy of wounds", looking at military memoirs, but especially at literature and art of the period.

What Science Fiction Can Teach Us about the Human Condition

King, Nancy M. P
nmpking@wakehealth.edu

Ursula Le Guin once said that science fiction is moral fiction. Good science fiction addresses moral choices more directly than does much other fiction. Good science fiction also offers an anthropological perspective on science and society. Taken together, these two features suggest that good science fiction can teach us about what it means to be human – a key concern of bioethics.

Three broad general topics can be explored through good science fiction from the last 50 years: the relationship between biology and culture, between biology and language, and between "wetware" and hardware and software. Addressing these topics (and others) through good science fiction can promote reflection on human society, culture, and morality: what they are and what they should be.

For example: Regarding biology and culture, Le Guin's *The Left Hand of Darkness* imagines a society where no one has gender except during fertile periods, when each person can temporarily become either sex. Margaret Atwood's dystopic *Maddaddam* trilogy speculates about how genetic alteration of the earth's flora and fauna could alter human society. The effects of biology on cultural differences are also highlighted by Nancy Kress's *Beggars in Spain* trilogy, which imagines a human society divided between those who need to sleep and those who do not; Octavia Butler's *Lilith* series, in which an alien race attempts to assimilate humans and does not entirely succeed; and many works by C. J. Cherryh, including the novel *Cuckoo's Egg*, in which a human is raised by an alien species, and the *Faded Sun* trilogy, in which a human soldier attempts to adopt and preserve the culture of an alien race's few survivors. Cherryh's *Cyteen* trilogy and a number of her other novels also address cloning, exploring social and cultural differences between cloned and naturally born humans.

Regarding biology and language, the novella by Ted Chiang, *Story of Your Life* (which became the movie "Arrival"), examines how human language is related to a linear perception of time, and considers what would be different if our perception were not of time as linear. China Mieville's novel *Embassytown* imagines an alien species whose language is performative, and who therefore cannot understand or use simile and metaphor. These writers take a deeply philosophical view of language and culture, and their works are both challenging and rewarding.

The biology-technology interface includes writings about artificial intelligence (AI), "cyborgs," or human-machine hybrids, and the cultural implications of radical life extension. Iain Banks' Culture novels address all these aspects of the combination of biology and technology, for example through characters that are both spaceships and very-long-lived beings. Many of William Gibson's novels and stories explore the nature and consciousness of AI, and the *Red* trilogy by Linda Nagata examines both the significance of enhanced human soldiers and the gulf between humanity and AI.

I will discuss two short stories (Le Guin's "The Ones Who Walk Away From Omelas" and Gibson's "The Winter Market") in detail, and make a reading list available.

Selfhood and patienthood in technologized home care

Kiran, Asle H
asle.kiran@ntnu.no

An older or frail person receiving care while living at home will frequently be offered some type of assistive healthcare technology. These types of technologies are expected to both ease the daily life of the care recipient and to make homecare delivery better and more efficient. Often, though, are the technologies met by scepticism and a worry that they will replace safe care and human-to-human contact. Coupling this with a shortage of expertise on use and time to train the care recipient, the result is that many decline the offer to use these technologies. Or, they are used only half-heartedly, resulting in a lack of ownership of the technology. The result the technologies are not being used (or used to their full extent).

This is unfortunate since the structural changes to health- and homecare that was behind the push for these technologies will go on anyway, potentially resulting in less help or less overall quality of care. Furthermore, care recipients miss out on some of the niceties that the technologies can provide when being used in the intended manner. When technologies are not being used the tendency is often to blame a lack of usability or some other functional shortcoming. However, as the above reasons suggested, the reason why home care technologies are not being used might pertain more to what the technology does to the life of the care recipient than usability-issues. It seems that home care planning often is based on an insufficient understanding of human-technology relationships. Consequently, we should expect that a better analysis of what it means and entails to be a care recipient in a technologized care setting will produce improved planning and implementation of assistive healthcare technologies.

In my talk, I shall attempt such an analysis, taking what it means to be a technology user as my starting point. Our lives are currently entangled with technologies in so many ways that we need to understand selfhood as being (co-)constituted by technological possibilities and constrains: what we regard as our existential potentiality – here and now, or in a lifetime perspective – can only be disclosed through the manner in which we relate to the assembly of technologies around us. Likewise with patienthood: we need to understand patienthood as being constituted through similar techno-social dynamics as a regular technology-conditioned selfhood.

To this end, I shall argue for the following: a) the parameters of patienthood is defined by the surrounding technologies regardless of being used or not; b) patienthood is lived by an individual, but is constituted by a collective consisting of both persons and things; c) patienthood is defined as much by its potentiality as by its actuality, and technologies can be principal in disclosing potentialities; d) the techno-social nature of patienthood infer specific moral responsibilities on technology developers, healthcare planners and workers, and family and next of kin. The goal of home care will always be *good care*, but how this is realised can only be figured out from a proper understanding of a)-d).

Changing Climates, Moving Minds: Climate, Geography and Health in Immigrant Fiction of the 19th and Early 20th Centuries

Langum, Virginia
virginia.langum@umu.se

The study examines the representation of mental and spiritual health in Scandinavian immigrant fiction of the 19th and early 20th centuries within contextualizing discourses of the nineteenth-century and early twentieth-century media reports (e.g., Smalley 1893), psychological studies (Ödegaard 1932), as well as discussions about climactic determinism (e.g., Draper 1867; Semple 1903). Many documents from the period witness “prairie fever”, the particular propensity to mental illness as experienced by immigrants to the North American prairies. Various theories were suggested, ranging from arduous circumstances, lack of a familial support system, inherent qualities in the immigrants themselves, as well as climactic determinism. For example, Ole Edvart Rölvaag’s prairie trilogy depicts a family who moves from the Norwegian mountains of the arctic to the Dakota prairie in the 19th century. Not only imbued with emotions and senses of its own, the prairie affects the actions, mental health and spiritual sensibility of its inhabitants. The celebrated first volume *Giants in the Earth* (1927), in particular, explores the impacts of the Dakota prairie on its protagonists’ mental health and outlook. For the optimistic Per Hansa, the blank expanse of the prairie is invigorating and inspiring, the climate challenging and fruitful. However, this same landscape and extreme climate leave his wife anxious. Her perceptions of the prairie contribute to her descent into madness that exhibits itself in a religious fervour yoked to her Norwegian traditions. Picking up the story decades later, the lesser studied second volume of the trilogy, *Peder Victorius* (1929), explores ideas of landscape and its impacts upon the psychology of the immigrants who have now settled the prairie and their offspring. Drawing from discourses contemporary with the novels, as well as more recent theories of climate and health articulated in environmental and medical humanities, this study will examine the intersection of physical, mental and spiritual landscapes in the novels of Scandinavian immigration to the North America. Finally, the paper will offer some reflections upon what these older novels might illuminate about contemporary narratives of environment, climate and migration.

Global Health Volunteering: Is Progress in Promoting Ethical and Sustainable Practices Undermined by Growing Role of Profit?

Lasker, Judith N; Siegel, Shira
jnl0@lehigh.edu

Background: Growing concerns about the quality and ethics of short-term volunteer trips in global health have led to the development of dozens of suggested sets of guidelines intended to promote best practices (Lasker, et al., 2018) and to the creation of websites and other resources intended to help potential volunteers select the best organizations (UMN GAPS). At the same time, there has been a growing for-profit sector recruiting volunteers and students and using misleading marketing and financial incentives to school officials to steer customers in their direction

Methods: Interviews with 25 college study abroad advisers and high school counselors inquire about methods used by companies, both for-profit and not-for-profit, to gain endorsement of short-term international service programs. Additionally, analysis of websites of the largest companies in the for-profit sector compares key messaging to the main themes in best practice guidelines. Other sources on social media allow for comparison of messaging to actual practices.

Findings: High school and college staff both reported being offered money and other benefits in exchange for directing students toward a specific organization. Analysis of organizational websites for both not-for-profit and for-profit organizations reveals a consistent emphasis on "community-based partners" and "sustainable" practices with "proven impact", consistent with most commonly recommended best practices. However, informal reports from returned volunteers suggest that these claims are often misleading if not totally false, particularly in the for-profit sector.

Discussion: Despite considerable agreement in the academic literature on the characteristics of good quality programs, there are few mechanisms to ensure that these are followed. There is also no reliable source of information about sponsoring organizations that would allow potential volunteers or host partners to know if they are working with a reputable organization that adheres to guidelines. These two realities open the door for companies to take advantage of the growing demand for overseas service opportunities by charging higher fees without having to invest in program improvements. This growing trend advantages higher income students who can use their experiences in building resumes and disadvantages host communities that are often overrun with unskilled and unprepared outsiders hoping to make a difference.

Regulating intelligence: the challenge of consciousness and competence in new forms of life

Lawrence, David; Morley, Sarah
David.Lawrence@newcastle.ac.uk

One forthcoming challenge for healthcare policy and regulation is the potential emergence of new types of being, both sapient and not, through advances in germline gene editing, synthetic genome technologies and the development of artificial intelligences (AI). It seems likely that these technologies will be the product of public companies and in particular multinational corporations. The main source of regulation for these bodies at present derives from company law, which is ill-equipped to handle the particular issues raised by these technologies. It may be that answers can be found in healthcare-focused regulation; including whether the beings they might produce should be accorded legal personality.

Recent proposals by committees of the European Parliament, the White House, and the House of Commons have suggested among other things the institution of degrees of personhood for extant 'expert systems' and autonomous robots. These proposals fail in several regards including quite how we might identify an intelligence deserving of this status.

Firstly, the granting of electronic personhood as they propose does not go far enough- corporate persons as they presently exist are a creation of commercial convenience and in no way possess any kind of 'human' or moral qualities. In certain circumstances and with particular technologies this may be an appropriate approach, however emerging bio- and cyber-technologies may occasion rights more akin to those of natural persons.

Secondly, regulators have reacted in a piecemeal fashion. It is imperative to first identify categories of morally significant products that would be subject to regulation and to what extent positive or negative rights might apply. We must therefore develop legal boundaries that might be used to determine between these products – a distinction which the authors term conscious and non-conscious beings.

This too may be overly simplistic a division. Not only are there degrees within consciousness of both sentience and sapience, there is the important point that consciousness does not equal competence (Gillick v West Norfolk). The technologies in question may have similar cognitive capacity to a human, but much in the way that children are not seen as competent to give consent to medical procedures it does not follow that a conscious synthetic being would be cognitively equal to an adult.

Incorporating subtleties such as this into the development of definitions will help us assess the extent to which a given technology should be liable under or protected by the law.

The paper will highlight the difficulties in this interplay between consciousness, responsibility, and liability, and attempt to provide a basis for developing workable legal definitions that may be applicable in many fields of law: including medical, company, human rights, employment, criminal and tort, amongst others. This goes far beyond the existing regulatory proposals and academic literature in seeking to move the focus from reacting to piecemeal issues (albeit important, such as negligence and automated cars) onto a more holistic and broad approach. Thus we ensure our readiness to keep pace with technologies that develop ever faster.

Critical thinking in bioethics. The Central America Initiative

Lazareff, Jorge A
JLazareff@mednet.ucla.edu

At a University Hospital in a high-income country (HIC) every treatment is available; hence what preoccupies the bioethicists and clinicians from HIC are the length of therapy in terminal stages of diseases or the triage process for the care of a malformed newborn,

The ethical priorities are different in Central America where there is no cardiac transplant program, no stem cell research, no state-of-the-art neonatal units and abortion is punished with jail even when the life of the mother is in danger. The role of Bioethics in Central America is to chart the decision process of scarcity and not of abundance.

In spite of this difference, the predominant subjects that preoccupy Latin American bioethicists, (Ibero-American Bioethics. History and Perspectives, 2010), revolves around the postulates of that are helpful in HIC. Our project aims at expanding the scope of Latin America bioethics by familiarizing clinicians and ethicists with the concepts of Critical Thinking. Our thesis is that bioethical choices are medical treatment decisions. The tenants of deductive, inductive and dialectic logic belong to a bioethical textbook as they do to one about internal medicine. We propose that through familiarity with philosophy, epistemology, and logic the clinician in a low and middle-income country (LMIC) will have the tools for searching evidence and determine treatment according to the specific reality that afflicts his/her patients. It will also provide a common language to ethicists and clinicians.

Moritz Schlick in "The problem of ethics" affirms that ethics is a science because there are ethical questions that have meaning and are answerable. And on that, we wholeheartedly agree; the ethical-clinical treatment process is a science. Schlick also states that the practical applications of correct solutions do not belong to ethics. And on that, we disagree, nothing is more ethical than giving the patient the best possible treatment. To determine the best possible treatment is in Central America and in any LMIC a matter for clinical and the social sciences.

Since 2014 we paired with Medical Schools from Central America to carry live Webinar series of consecutive, 2-hour long lectures, on Critical Thinking in Bioethics with emphasis on the logic process of treatment decision. We cover inductive and deductive logic, fallacies and causality. The cases analyzed revolve around situations such as assigning operative room time to a child with pain secondary to tethered cord over a patient with stomach cancer, or a variation of the trolley dilemma; one ambulance and two acutely ill patients at an equidistant but opposing distance from the hospital.

Three hundred and fifty-six graduates and undergraduates of medicine, nursing, psychology, have completed the course. Six universities from the region are enrolled for 2018. We are working on a manual for critical thinking on the ethics of treatment in Central America based on clinical experiences provided by the participants. The critical analysis of the role of physicians assisting in torture will included in the second semester of 2018.

Compassionate Use of Investigational New Drugs: A Real Option for Patients?

Lin, Shin-Rou
shinrou@mail.cgu.edu.tw

Do terminally ill patients who have exhausted all other available, government-approved treatment options have a right to experimental treatment that may prolong their lives? Of 28 EU states, 18 have established its regulations and processes for the so-called compassionate use program (CUP), under which patients that do not meet the inclusion criteria of clinical trials are able to access therapies unapproved by the government. In 2016, because of advocates' pressure, Taiwan Department of Health also introduced a new mechanism permitting access to unapproved human cell treatment after sufficient clinical evidence of safety and effectiveness of the products are confirmed. Allowing patients to try unproven treatments, outside of controlled clinical trials, risks both the validity of the scientific study and the health of current and future patients who stand to benefit from the deliberate, careful new drug approval process as it currently operates under the regulatory framework. A range of constituents, including terminally ill desperate patients, pharmaceutical companies, government regulators, physicians and the public all have important but conflict interests in ethical issues in expanded access to experimental drugs. Compassionate use also faces challenges in stipulating eligibility, review processes, and oversight mechanisms to reconcile the protection of vulnerable patients from the use of products that may be useless or worsen their conditions with the provision of opportunities to access to treatments that may be beneficial. Empirical data on the U.S. compassionate use program shows that the U.S. FDA has permitted almost all compassionate use requests but only 2% of programs reported results. The powerful moral duty of rescuing those in very dire straits may well blind us from seeing the fundamental concept that led to the CUP at the outset: that having access to treatments that are ineffective may not be in the interest of patients and may in the end be harmful to their health status.

Animalism and Death

Lizza, John P
lizza@kutztown.edu

Animalists, such as David DeGrazia and Don Marquis, reject total brain failure as death, because they identify the human person with an integrated human organism and maintain that the brain is not necessary for a human organism to be biologically integrated. Pointing to the high degree of somatic integration in brain-dead pregnant women who are artificially sustained for weeks or months to allow the fetus to gestate so that it can be removed by Caesarean section and the extraordinary case reported by D. Alan Shewmon in which a whole-brain-dead body was artificially sustained for over twenty years, these theorists maintain that death has not occurred despite total brain failure. I critique this view on grounds that, since the same degree of organic integration in an artificially sustained human body with total brain failure may be present in an artificially sustained, decapitated human body, rejection of total brain failure as a criterion for determining death would entail that artificially sustained, decapitated human bodies would be living human persons. Because there is no practical, moral, or legal reason to count artificially sustained, decapitated human bodies among the living "we," there is no practical, moral, or legal reason to count artificially sustained human bodies with total brain failure among the living "we." Both are in some sense the live remains of human persons, and thus the human person has died. By artificially sustaining whole-brain-dead bodies or (hypothetically) decapitated bodies, we have intervened in the natural process of dying and made it possible for a human person's remains to now take the form of an artificially sustained organism of some sort devoid of any potential or capacity for consciousness and any other mental function. To count such beings among the living "we" would involve a radical distortion of what it means to be a living human person, i.e., one of us. Treating such individuals as human persons has no place in our moral and legal framework, which is the framework in which we need to formulate criteria for determining death. Thus, the animalist view of the human person that underlies the rejection of brain death as death does not fit well into our moral, social, and political systems of thought. The moral, social, and political framework is about human persons understood as not only biological beings but as psychological, moral, and social beings. Since animalism considers psychology, moral standing, and social relations to be non-essential to our existence and persistence, it invokes a concept of our nature that is useless in a framework that assumes an alternative concept of the kind of beings that count among the living "we." In short, animalism is an unhelpful theory about our nature to navigate the terrain of bioethics.

Narrative Medicine: A pedagogical revolution in medical education

Lizza, Sofia
sofia.lizza@ehess.fr

Narrative Medicine has grown as a discipline since the 1990s, uniting primary care medicine, the humanities, contemporary narratology, philosophy, and the social sciences. The purpose of this field, first coined by Dr. Rita Charon, is to "recognize, absorb, metabolize, interpret, and be moved by the stories of illness." Narrative Medicine focuses on listening to the patient's story and their medical experience, often interrupted or neglected by health professionals. This discipline emerged as a reaction against the teaching and practice of medicine in the United States, primarily due to the corporatization of medical care within managed care systems. The progression of medical technology towards personalized medicine draws away from the interaction and listening between patient and caregiver. I do not doubt the value of these advancements, particularly in preventative medicine, but they do change the way health professionals care for, or rather, treat their patients. Narrative Medicine has developed into a recognized field and is being taught and practiced worldwide, primarily in the United States, France and Portugal. This discipline has strong implications within the practice of palliative care, a specialty in which the patient's beliefs and values play a large role in their medical care and end-of-life decisions. The growth of evidence-based medicine (EBM) in medical education and medical care privileges clinical decisions made on evidence, bypassing the singular case and individual story of the patient. Narrative Medicine proposes a patient-centered care approach that acknowledges the narrative features in all medical "evidence." Charon and colleagues call for "Narrative Evidence-Based medicine (NEBM) instead. Reflecting on a patient's story in medical decision-making can lead to better patient outcomes. Although Narrative Medicine grounds itself in major themes throughout the history of medicine, i.e. physician-patient relationships, I argue that its interdisciplinary approach and current focus in medical curricula render it a revolutionary discipline in medical education and medical care, particularly within the field of palliative care.

Lost in Translation? Rethinking Informed Consent for 'mHealth'

Loosman, Iris
i.loosman@tue.nl

Mobile Health promises transformation of the health-care industry and is predicted to enable more personalized, participatory, preventive and less expensive care (Malvey 2014). Mobile Health (or: mHealth) provides health-related information or health care services to individuals through digital mobile devices. These technologies can transform the mode and quality of clinical research and health care on a global scale. Real-time data and wearable sensors will enable care and enhance users' understanding of their own wellbeing. My specific area of focus within mHealth is that of mobile support systems for behaviour change: mHealth specifically designed to help users behave healthier, for example through Fitbits or diet apps. Increasingly, mobile support systems for behaviour change will start acting as artificial agents, supporting the user in their daily life. But besides the many opportunities this rapid innovation provides, there are still some challenges to overcome.

One of the most important ethical issues raised by support systems for behaviour change is consent (Spahn 2012), which is also a bedrock ethical value in medicine (Beauchamp 2011). Mobile support systems for behaviour change pose special problems for consent, because they are ubiquitous, data-intensive, and involve artificial intelligence. It is often difficult to know the underlying processes by which technologies for behaviour change influence behaviour, to predict the (secondary) effects they might have on individuals and society, and to implement effective mechanisms and procedures for monitoring those effects. These technologies collect extensive data with many potential uses, but the exact uses are difficult to describe and evaluate in advance. This makes it difficult to trust them and to consent to their use.

mHealth bridges the clinical context on the one hand, with the context of everyday life on the other. This leads to blurring of the relevant norms, between care norms, and general information technology norms. As a result, the norm-based expectations that normally frame and ground consent to a treatment may not be clear, or even absent altogether (Voerman & Nickel 2017).

In this paper, I aim to rethink informed consent for the context of mHealth and develop a new consent model: *Distributed Consent*. Current consent procedures in mHealth fail to protect fundamental values we expect and want to be protected in contexts of treatment or behaviour change. An example of such failed consent is clicking 'Agree' without reading what is being consented to. I approach this project in terms of translation – the conversion of something from one form or medium into another – which requires careful analysis of meaning in order to preserve this meaning after conversion. By analysing three different components of consent, namely autonomy, communication and decision-making, and the shifts that occur in translation, I show that the medical care context is a much more fruitful resource to draw on in rethinking and ultimately redesigning consent in mHealth. Distributed Consent will not only protect and respect the underlying values of consent, it will do so in a way that optimally utilizes mHealth's technological opportunities.

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Pregnancy, Labor and Birth in Between Philosophy and Medicine

Malagrinò, Ilaria; Russo, Maria Teresa

ilaria.malagrino@uniroma3.it

Philosophical speculation has long passed over pregnancy, labor and birth in silence because its theoretical categories fail to capture such experiences. Clinical treatises depict them as anonymous phases and moments of fetal development, objectively observable and controllable biological processes. But both Philosophy and Medicine leave behind human procreation as an experience of 'pregnant embodiment' with important and urgent ethical consequences. The aim of this paper is to analyze the thought of Julia Kristeva and Iris Marion Young in order to show the importance of a phenomenological study on pregnancy, labor and birth focused on the category of subjectivity. This perspective makes use of philosophical and medical knowledge, but at the same time it is a challenge to both.

Three reading models for cancer narratives

Martínez, Ramón
rm3504@columbia.edu

Cancer narratives offer readers a multidimensional account of a patient's cancer experience. Although these narratives have become an important teaching component in today's medical education, not all types of cancer narratives are equally represented in the curriculum. For this reason, there is a need to focus on marginalized narratives, such as those about prostate cancer, as a way to shed light on new narrative sources and methodologies that can enrich health humanities programs. While current narrative analysis tools have proven useful to understand illness narratives, in general, there is a need for novel reading models that allow for a complete analysis of the complex narrative framework of cancer narratives. This study aims to develop three narrative reading models by building upon Rita Charon's reading methods and Arthur Frank's illness theories. The three models are developed by applying them to a diverse sample of prostate cancer narratives. The first model developed uses Frank's quest story to focus on a narrative view of all illness-related events. Not only does this method help readers view illness as a journey with various stages, but it also allows readers to identify specific fears patients have about the diagnostic and treatment procedures. This method aids in the identification of the differences in perception between some of the narratives by white men and African American men, or patients and patient-doctors. The second model focuses on the patient-doctor relationship, emphasizing the communicative behaviors of patients, doctors and patient-doctors. Through the second model, an analysis is carried out of the way that narratives characterize hierarchical social divisions and the internal psychological battles that patient-doctors and doctors have about being *reduced* to a patient. The patient-doctor's and doctor's own verbal and non-verbal communicative behaviors are observed. The third approach examines the embodied/psychosomatic impact of prostate cancer and how the experience of the illness and treatment choices are related to a patient's concerns about family and sexual relationships. This method provides a clearer view about how men cope with a disease that threatens the epicenter of a man's life and identity. It also allows for scrutiny of the various notions of masculinity that are conceptualized in relation to prostate cancer, in terms of race, social status and professional background. In conclusion, these three new reading models devised provide health professionals, especially medical students, with another set of tools and skills to fully understand the multiple dimensions in the cancer journey, especially of those patients of prostate cancer. Thus, this study presents a new pathway to gain medical competence, which is based on the acquisition of narrative competence and reading strategies in order to understand autobiographies by cancer patients.

Neuroethics in dementia prevention: ethical issues in early intervention for better lifelong brain health

McKeown, Alex
alexander.mckeown@psych.ox.ac.uk

We examine ethical questions raised by findings from ROADMAP, an EU-funded project aiming to improve outcomes in Alzheimer's disease. The growing impact of AD is driving its reconfiguration as a public health issue away from one of standard remedial clinical medicine. Health policy is moving towards an early intervention model for reducing its incidence. This raises important ethical issues in relation to key themes of relevance mortality and death; the reconfiguration of medicine; and progress and sustainability.

First, in AD the aim is to develop means by which healthy individuals can a) make lifestyle choices for risk reduction; b) take biomarker / genetic tests for risk disclosure. This poses ethical questions, for example, when we should intervene. We might assume it better to know one's risk as early as possible so preventative action can be taken. However, this risks medicalising ageing, tacitly redefining health as (pre-symptomatic) illness. While AD is considered a disease of older age, predictive tools will focus on younger adults. Political will endorses early intervention and younger people will face difficult choices regarding risk disclosure and information of variable accuracy about their future. The drive to create new and lengthier norms of health changes expectations of mortality, which affects what we might understand as a normal narrative arc of health throughout life. Such changes may be pernicious if it becomes possible to make accurate predictions of AD early in life, as until AD is curable, knowing that one is precluded from certain life choices and goals may have a profoundly negative impact on individuals receiving the prognosis.

Second, treating AD as a public health target shifts its management towards a strategy of enhancement. Many public health successes enhance, for example vaccination, sewer engineering, water purification. Each has delivered improved health norms across entire populations, to the healthy as well as the sick. Once the constraint of normal health remediation in standard clinical medicine is removed, it is not obvious what we should do. The bioethical debate surrounding ageing is relevant if it becomes an intrinsically harmful one to be avoided through prevention. In this way recasting AD in public health terms also reconfigures the boundaries of medicine, and we should consider how far to move those boundaries. For example, we might assume it desirable for as many people as possible to live more healthily for as long as possible. While this assumption is laudable at an individual level, it requires scrutiny at a population level. It is true that the ability to create new and better norms of health counts as progress, but such successes pose challenges for sustainability, as an ageing and expanding society will become increasingly difficult to support unless strategies for dealing with these demographic changes are designed and implemented.

Evaluating issues of this kind arising from projects such as ROADMAP is important for understanding the long term goals of better (brain) health and creating the conditions for their realisation.

Extreme Body Modification: Between Bioethics and Body Art. Hybrid/Cyborg Art and Amputation on Request

Michałowska, Monika
monika.michalowska@umed.lodz.pl

The issue of body modification for non-medical reasons has been considered as one of the most problematic and thought-provoking in bioethics and medical ethics. Among various forms it can take, such as cosmetic surgery, sexual reassignment surgery, amputations of healthy limbs on request, the last one − known in the subject literature as ‘wannabe amputee’ − seems to be the most controversial. It is also the one that meets with most critical arguments refusing wannabe amputees the right to decide about the look and shape of their body. Apart from the medico-moral rule (*Primum non nocere*), others concentrating on wannabe amputees' lack of competence to make autonomous decisions have been usually formulated.

Simultaneously, for several decades we have been facing a cultural phenomenon of surgery for the sake of art. Body art performances have been already recognized as challenging the well-established concepts, assumptions and beliefs concerning the mind-body relation, and are considered ground-breaking cultural phenomena that cross the boundaries of art, medicine, technology and bioethics. This interdisciplinary and provocative approach becomes the very essence of the performances of hybrid artists or cyborg artists who subject their own bodies to modifications, enhancement and technological transformation. However, despite very controversial – and to some even repulsive − reasons they give for the modification of their bodies, the autonomy of art performers such as Stelarc, Orlan, Vanouse, Neil Harbisson or Moon Ribas – who actually called themselves hybrid and cyborg artists − have not been questioned and the surgeries on their request for the sake of art have been performed. What is more, an additional argument concerning the public interest in supporting the arts has been used in this debate in favor of societal and ethical acceptance of extreme body modifications.

In my presentation, I will take a closer look at the issues of the surgeries for non-medical reasons focusing on the two abovementioned phenomena. I will analyze the examples of each of them, taking into account both the reasons the wannabes/artists give, and the arguments surgeons provide to justify their agreement or refusal to perform this kind of surgery. Then, I will trace the arguments formulated in the subject literature for and against each of the two kinds of surgery for non-medical reasons. Finally, I will discuss whether there is a significant difference between a surgery for the sake of art and a surgery at the request of 'wannabe amputees' that would explain and justify societal approval or/and ethical acceptance of one of them and societal and ethical rejection of the other.

How to account for the experience of pregnancy in a phenomenological perspective

Miglio, Nicole
ninicole.miglio@gmail.com

In this talk, I will defend a conception of pregnancy as a paradoxical form of embodiment, namely a process of essential changes of the personal identity and an acquisition of a new range of cultural and existential meanings and potentialities for the subject. The theoretical framework in which I shall develop my thesis is based on the following slogan: at the same time, a pregnant woman *has* and *is* pregnancy. Moving from the phenomenological distinction between Lived body (*Leib*, *Corps Vécu*) and Objective body (*Körper*, *Corps Objectif*) (Plessner, 1928; Husserl, 1929; Merleau-Ponty, 1942), I shall argue that: (i) She *has* pregnancy, to the extent that she happens to be in a status that involves specific physiological phenomena; (ii) She *is* pregnancy, in the sense that pregnancy may be conceived as an embodied relational experience that causes several changes in (a) the auto-representation of the pregnant woman, as well as (b) her body schema, body image and sense of agency. The core of my thesis is that, in the bodily experience of pregnancy, one's identity is decentered and doubled in several ways. The idea that she *has* pregnancy is included in my account as long as the passive aspect is strictly part of the whole human experience. The duality *Leib*/*Körper* will be useful in a heuristic perspective, if we consider (i) and (ii) linked by *vel*, and not *aut*.

As Young (1984) pointed out, in medical literature the self of pregnant woman is reduced to her body, a container where some biological processes take place. I claim that this paradigm, which is a version of the idea that woman *has* pregnancy (see (ii)) and of the so called "foetal container model" (Kingma, 2015), arises from the classical Cartesian conception of the subject:

the (pregnant) subjectivity at the stake of debate is dis-embodied and split in body/mind distinction. It is highly problematic for several reasons:

1) It accounts for *neither* the part-whole relationship, *nor* the peculiar oscillation between unity and duality of pregnant woman/foetus couple. As Tyler (2000) and Sidzinska (2017) underline, this conception is based on principles of masculine embodiment such as discreteness, self-containment, and temporal stability;

2) It lacks to explain the pregnant subject's point of view, not naïvely in the sense of auto-narration of the experience, but more incisive in the issues concerning the peculiar variations of motility, spatiality and time (Young, 1984; Heinämaa, 2014);

3) It ignores the interplay of socio-cultural norms and physiological legacies, because of the lack of a phenomenological focus on qualitative variations in the common experience of pregnancy.

I suggest that pregnancy is that kind of experience in which the polarity between lived body and objective body is made more perspicuous. Through the analysis of Young's (1984), Welsh's (2013) and Heinämaa's (2014) accounts, I shall argue that pregnancy is the form of embodiment that, being constitutively rooted in polarities such as activity/passivity, self/other, inside/outside, challenges these in radical ways.

Human dignity and the limits of human enhancement: Dignity, authenticity and human enhancement in movie *Limitless*

Milinkovic, Igor
igormilinkovic@yahoo.com

The rapid advancement of medical technology creates unprecedented opportunities for the selection and improvement of human characteristics. By using genetic engineering or pharmaceuticals, it is possible to improve human abilities, not only within the framework of therapeutic elimination of pathological conditions, but also above the level of normal functioning. The complexity of ethical dilemmas arising from the uses of enhancement technologies did not escape the attention of movie makers. One of the movies that successfully explored ethical dilemmas of human enhancement is the movie *Limitless* (2011), based on the novel *The Dark Fields* (2001) by Alan Glynn. The movie follows the story of a relatively unsuccessful writer, who thanks to an experimental drug becomes extremely successful in all areas of his work. The question that will be explored is whether the main character's actions can be reconciled with values of human dignity and authenticity?

In the first part, the basic ethical dilemmas surrounding the application of enhancement technologies will be examined (the emphasis will be put on the role of human dignity within human enhancement discussions). Although value of human dignity is often used to justify conservative attitudes (and, accordingly, to criticize use of enhancement technologies), transhumanists themselves try to defend human enhancement by referring to this value. The choices made by the characters from the movie will be analyzed from the perspective of values of dignity and authenticity. The question will be addressed whether these choices can withstand the dignity and authenticity test. The parallels will be drawn with other movies dealing with similar themes and the fates of their characters will be compared (e.g. Gattaca). The transhumanists' understanding of dignity will be subjected to criticism, with a particular emphasis on the value of authenticity.

The 100K genomes project & rare disease: a return to geneticization?

Miller, Jane
Jane.Miller@qub.ac.uk

The term geneticization was coined by Abby Lippman in 1991 to convey the influence of genetics over medicine, people and their identity. She described it as an 'ongoing process by which priority is given to differences between individuals based on their DNA codes, with most disorders, behaviors and physiological variations … structured as, at least in part, hereditary.' (Lippman 1991). This theory has been widely criticized by social scientists who now favour a broader concept of biosocial model which encapsulates all the determining factors that input into one's health and identity. However in the field of rare disease, genetics is playing a major role with the 100K genomes project aiming to sequence the whole genome for participants with a rare disease. Is this a return to the geneticization thesis or are there other factors at play?

I will present some testimonials from patients and their parents and/ or carers to show the importance of genetics to them and its value. The value of this 'labelling' can be seen in the existence of SWAN UK, a charity for those with a syndrome without a name. Thus even those without a disease specific support group or charity to which they can belong can be part of a supportive network. In his 2016 paper Arribas-Ayllon acknowledged this 'social' value of genetics stating that 'where conditions lack clinical coherence, genomic explanations have the power of producing new kinds of people. Even when the science is partial and where conditions are poorly understood, the ability to create identities around genomic mutations is enough to create new communities of shared recognition.' (Arribas-Ayllon 2016). I will argue that the 100K genomes project is not seen as a geneticization of participants' lives and their conditions but rather a way of affirming their disease and possibly providing an explanation. It can also, if they receive a diagnosis, point them to specific support groups, possibly improve their health care and even their access to different forms of care and benefits.

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The Abolition of Medicine and Health Care

Mosteller, Timothy
tmostell@calbaptist.edu

75 years ago, C.S. Lewis published *The Abolition of Man*. This book is an excellent example of how deep thinking about the nature of ethics can arise from the humanities and apply directly to medicine and health care. In *The Abolition of Man*, Lewis sounded a warning call about the use of advanced medical and health care technologies in the hands of those who reject what he calls the *Tao* (i.e. "Doctrine of Objective Value"). This is "the belief that certain attitudes are really true, and others really false to the kind of thing the universe is and the kinds of things we are."

This paper for the 2018 ESPMH conference seeks to apply Lewis' argument (which arose from a literary problem appearing in text books for young people) to contemporary thinking about the very nature of medicine and health care. I argue that Lewis' conclusion that an axiologically rudderless approach to medicine and health care lacking a commitment to the objectivity of value entails that both medicine and health care are impossible. This is of special importance given both the current reality of powerful technologies (e.g. CRSPR/Cas9) which were unknown in Lewis's time, coupled with the possibly even more radical technologies unfolding in the next seventy-five years (e.g. artificial intelligence, trans-humanism).

The argument of this paper has four parts. First, I consider Lewis' "Doctrine of Objective Value." I argue that it is not only a coherent approach to ethics, but that it is more reasonable than subjectivist approaches. Several reasons for this will be put forward. Second, I offer an assessment of Lewis' argument against those he calls "The Conditioners" who by means of advanced scientific technology can mold and make our species into whatever they wish them to be, including whatever they wish our species to believe about the nature of value. Several objections to Lewis' argument will be considered and rejoinders given. Third, I offer a conceptual clarification of why a rejection of the doctrine of objective value entails the impossibility of both medicine and health care. Finally, I conclude by considering Lewis' own solution to the difficulty of surrendering the objectivity of value to scientific advancement. I argue, following Lewis, that the objectivity of value must apply to all areas of human inquiry (including and especially scientific inquiry) or face specific logical absurdities, and that this is especially the case when considering the flourishing of medicine and health care.

Ethical Considerations on Health Tracking in the Occupational Health Context: An Evaluation.

Müller, Sebastian; Kuhn, Eva; Buyx, Alena; Heidbrink, Ludger
mueller@philsem.uni-kiel.de

Health tracking is not just a lifestyle activity for ambitious sportsmen and self-improved high performers but an emerging tool for occupational health management (OHM). Some companies organize challenges where co-workers and departments compete for "most steps registered" on their smartwatch. Others provide smartphone apps that allow their employees to manage stress or control their diet. Smart devices can record sleeping habits and stress, count steps or heart beats and track one's location at any time. In the work context, this data can be collected systematically and be accessed by the employees themselves and/or authorized personnel. This way, the company and the employees can spot health issues early and provide and access preventive measures based on quantitative data.

There can be downsides to such a work health environment. The most prominent critique deals with data transfer, security and data trading. Besides that, there are two underexplored ethical downsides to health tracking techniques in the occupational health context, namely problems of justice and autonomy. They provoke questions like: Who should be responsible for the tracked health data? What medical knowledge do personnel need to have to understand the tracked health data properly? Is the OHM team incentivised? Do they need to trade off employees' individual health for the company's overall profit? On the other hand, there are autonomy issues that emerge from the tracking option. Do employees understand the possible consequences of this technique? Do they feel free to engage with or decline it?

Like most other ethical OHM problems, this reflection is trapped in an interface of business ethics and bio ethics and needs to be solved in that interplay as well. We will evaluate the application of health tracking in the occupational health context by mediating between both concepts on a theoretical level and we will use a qualitative multi-stakeholder interview study on the interface of corporate social responsibility (CSR) and OHM. Finally, we will provide a rational that will allow companies to identify proper ethical structures and occasions in which it is appropriate to use health tracking technology.

The Passive Aspects of Human Condition as an Argument Against Human Enhancement

Münch, Nikolai; Mahdiani, Hamideh
nimuench@uni-mainz.de

The advances in CRISPR-Cas-Technology have given rise to ethical concerns about its possible use for purposes of human enhancement (HE) (e.g., Lanphier et al. 2015; Baltimore et al. 2015). Whether or not HE is permissible, desirable or even obligatory, in moral terms, has been discussed among ethicists since decades without reaching a commonly accepted answer. Erik Parens suggested this is due to the fact that proponents and opponents of HE are working with different ethical frameworks which grow out of „different [...] experiences and understandings of our selves and of our proper relationship to the world“ (Parens 2005: 37). We propose that one important - but yet not described aspect – is that proponents and opponents of enhancement have a different stance on how to value and deal with the passive or patiential features of the human condition. For this objective, we will analyse philosophical and fictional texts on HE in three steps: We will sketch the passive features of human condition (1), show what role they play in fictional texts which take a sceptical or at least ambivalent stance against enhancement (2), and finally we claim that this stance or understanding of the self and its relationship to the world is not only present in fictional texts but also underlies philosophical and ethical criticism of human enhancement (3).

(1) Passive features of the human condition: In Western philosophy in general and in modern philosophy in particular passive features of human condition are quite marginalized. Passivity often is linked to sensuality and/or corporeality which is the other side of active human reason. It is active human reason and autonomous human agency that mark the essence of modern self-understanding. Enhancement can be understood as a technical means to expand the possibilities of human agency and control. However, recently there is a growing philosophical interest in the marginalized passive aspects of human existence: “On the balanced view […] passivity, inability, necessity/contingency and dependency are as constitutive of personhood as the ‘positive’ aspects of action, capability, choice and independence.” (Reader 2007; cf. Münch 2017) This shifting focus seems not only to be present in feminist discourses on e.g. vulnerability but also implicit the discussion of human enhancement – in fictional and philosophical texts alike. In what follows we will argue that this is an important source of scepticism against HE.

(2) Scepticism against human enhancement in fiction: Following Wolfgang Iser’s theories on phenomenology of reading, Otmar Ette proposed that since fictional texts are always ahead of our practice of life, their portrayed worlds provide readers with a “space of experimentation” where they can “test out different life situations”, and thereby “engage to collect experiences that they could not have in real life” (Ette 2010: 987) in at least two ways: intratexually, and extratextually. This way, fictional worlds of novels can be understood as microcosmic depictions of different types of knowledge for living. In these imagined worlds, symbolic representations of objects or living entities and thematic choices of the author are of great significance. This article looks into three literary texts: William Gibson’s 1984 *Neuromancer*, Henry Mulisch’s 2001 *The Procedure*, and Michel Houellebecq’s 2006 *The Possibility of an Island* to advance an understanding of HE debate that is informed by cultural manifestations of ethical perspectives on technology.

(3) The passive features of human condition and philosophical criticism of enhancement: Finally, we will show how Jürgen Habermas tries to work out an argument against enhancement based on the passive aspects of human corporeality (Habermas 2003; 2008) and compare his argument to Michael Sandel’s criticism of enhancement (Sandel 2007). Sandel, too, bases his arguments on the passive aspects of human existence and argues for an appreciation of the gifted character of human life.

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Will-o'-the wisp of moral neuroenhancement

Neiders, Ivars
Ivars.Neiders@rsu.lv

If one takes just a casual look into moral enhancement literature that has been produced during recent years it is very hard not to notice a considerable change in the mood that has taken place just in few years. Initial excitement and optimism expressed by some authors just about ten years ago now seems to be unjustified and exaggerated. In contrast to that the recent publications tend to be rather modest in their claims. For example, just ten years ago I. Persson and J. Savulescu wrote that there is "urgent imperative to enhance the moral character of humanity" (Persson & Savulescu 2008). Just few years later de Melo-Martin and Salles referred to moral enhancement as "much ado about nothing" (Melo-Martin & Salles 2014). In the paper I will address two issues. First, what are the main reasons of this change, and, second, what lessons we can learn from that.

What is Wrong with Ludovico's Technique: Moral Enhancement in "A Clockwork Orange"

Neiders, Ivars
Ivars.Neiders@rsu.lv

Ludovico's Technique is a fictional aversion therapy described in Anthony Burgess's novel "A Clockwork Orange". The purpose of the therapy is to induce aversion to violence so that people who are inclined to commit violent acts can be turned into well-behaved citizens. As such Ludovico's Technique can be described as a kind of moral enhancement. It works by injecting a subject with a substance that induces nausea and then forcing him or her to watch violent films. Due to the therapy, every time when the subject conceives a violent act he or she experiences strong feeling of nausea and as a result is made incapable of violence. In the novel the therapy is used to treat 15 years old thug called Alex. Alex is a sadistic gang leader who enjoys violence, he and his friends entertain themselves by beating people up, raping and sometimes even killing them. After a conflict within a gang Alex's friends betray him and he is put into prison. Here he is offered to participate in the experiment of Ludovico's Technique. Alex decides to give it a tray, the treatment turns out to be effective and Alex is allowed to leave the prison. Burgess himself found the treatment morally wrong, and so do, I think, many readers (and viewers of Kubrick's film, that is based on the novel). But what exactly makes Ludovico's Technique wrong? The unnamed prison chaplain who seems to be Burgess's mouthpiece in the novel, offers an answer. He points out that the main problem with the treatment is that it deprives Alex of choice. “Goodness”, he says, “is something chosen. When a man cannot choose he ceases to be a man.” This diagnosis in many ways is similar to that offered by some contemporary bioethicists (e. g. John Harris) as an objection to moral enhancement. In the paper I will argue that chaplain is only partially right (at beast) and there are other problems with the technique, that make it morally objectionable. The discussion will shed light on some important issues in the current debate about moral enhancement.

What stands in the way of excellent e-coaching?

Nickel, Philip J
P.J.Nickel@tue.nl

Electronic coaching (e-coaching) for health is the use of smart mobile technology to provide automated feedback that helps a person achieve certain health goals such as optimal management of a chronic illness, or achievement of fitness targets. It employs automated, context-sensitive judgment to generate advice, and often makes use of artificial intelligence. It can be seen in a range of wearable devices that people use to bring their physical activity and sleep habits into line with best practices.

In this paper I consider the distinctive excellence of e-coaching. Drawing on the idea of coaching as well as statements from the literature on e-coaching (e.g., Beun et al. 2016; Nooitgedagt, Beun & Dignum 2017; Lieffers 2016), I argue that the function of e-coaching is set by *the coachee’s end* (e.g., to play beautiful tennis). An e-coaching service uses automated information collection and processing to provide (motivational, informational) resources to *help me specify and achieve my end in context*. An excellent service does this reliably (non-accidentally). I presuppose a broadly Aristotelian account of functional excellence.

There are two main difficulties for e-coaching to carry out its function well. First, an e-coaching method has to have a successful way of determining when the user’s failure to comply with their goal related behavior is a case of weakness of will or simple forgetfulness, and when it stems from a different source, like a reordering of priorities.

The second difficulty is “specifying ends in context.” When goals are formulated in a general way, such as ‘to stay healthy’, or ‘to manage my diabetes’, they are easily shared. But when the e-coach translates such general goals into more specific instructions for behaviors and plans, such as ‘to avoid eating junk food for the next twenty minutes’, she may find that the person receiving these instructions has a different interpretation of how important the goal is, and how best to achieve it. E-coaching has to be able to do this in order to count as serving the ends of the coachee, rather than imposing a particular specification of those ends.

When e-coaching does not overcome these difficulties, *functional* failures can result in (unintentional) hard paternalism and a failure to be excellent all-things-considered. When the e-coach imposes an interpretation of non-pursuit, or wrongly specifies the end in context, this can result in (unintentional) hard paternalism, because the e-coach imposes a goal I have dropped, delayed, or reprioritized; or because it imposes a specification of the goal in context that I don’t share.

To address these challenges, I propose combining e-coaching services with self-coaching and human coaching, in a hybrid socio-technical system. To make e-coaching excellent all-things-considered, we should try to overcome its functional limitations through hybrid modalities. It is possible, for example, to use peer coaching or guided self-coaching in order to improve the mutual awareness, situational awareness, and personal knowledge of the socio-technical system as a whole, without becoming too resource-intensive (i.e., requiring the input of medical experts).

When Listening Fails: Barriers to Effective Receiving of Trauma and War Narratives

Nunes, Antonio
abn2132@columbia.edu

Listening sounds nice. Listening allows us to become acquainted with other's narratives, likes and dislikes, humor, family history, and more. It is indisputable that listening to one another has the potential to increase connection and intimacy between individuals. Listening, or receiving an account of another individual or group, appears to be beneficial for both the account-giver and the account-receiver. But it is well documented that adequate listening does not always happen. Sometimes the story is received and unjustly altered, rejected, or forgotten. Sometimes the story is never told. These are the times when the exchange breaks down between individuals. This phenomenon occurs ubiquitously, but it becomes even more salient in the case of war and trauma narratives. What are the barriers that lead to such a breakdown in listening and account sharing? I turn to the storytelling of war and trauma in Dr. Jonathan Shay's *Achilles in Vietnam* and Tim O'Brien's "How to Tell a True War Story" from *The Things They Carried* for investigation. This paper will explore the times when listening fails in these texts in order to elicit and identify the barriers to effective listening I will argue that listening often fails when the moral implications of listening overwhelms the listener, the risk of stigmatization of the listener is too high, and when the listener is unable to accept narrative's inherent inexpressibility. Finally, I conclude that listening is a political, moral, and existential act, and the listener must come to grips with its own morality and the pressures of its social circumstances to listen in a way that does not deny nor forget. The effective listener must accept that war and trauma stories do not have clear resolutions or easily applicable language to soothe the inherent ambiguities and inexpressibilities. If listeners can achieve these tenets, the most effective listening can be had, and the victims of trauma can distribute some of the burden of their trauma to the listener. This "communalization of trauma," as Shay puts it, is essential in the recovery of survivors. If these tenets are not met, listening fails and the recovery process is stalled. This failure is particularly insidious in clinical, counseling, or other health care settings. Thus, these conclusions can be particularly useful to better understand listening in the clinical setting and improve patient-clinician relationships.

Defining aging as a disease makes the disease concept nonsensical

Pahle, Andreas; Hofman, Bjørn; Vogt, Henrik
andreas.pahle@gmail.com

Spurred by new technological opportunities, various agents currently argue that aging should be defined as a disease and included in the revised International Classification of Diseases (ICD-11). One common argument for this view is that diseases (for instance cardiovascular disease, cancer, and Alzheimers Disease) are regarded as expressions of a more fundamental pathological process, namely aging - and that aging in itself should therefore be regarded as a disease. We argue that by defining aging as a disease, the disease concept becomes nonsensical. An important premise for the argument that aging is a disease is that there is a false dichotomy between disease and aging (senesence). We agree that there is no clear physiological boundary between disease development and the aging process. However, just as there is no clear boundary between aging and disease, there is no clear boundary between aging and the process of life as such. So, if one accepts that aging is defined as a disease, one is forced to accept that *life as such* (e.g., defined in terms of self-producing and self-sustaining systems including their historical-collective organization) *is a pathological process*. It also follows that, since all living beings are aging, all living beings will be diseased. Hence, the concept of disease will lose its discriminatory function. If all living beings are diseased, the concept of disease loses its meaning.

One might argue against our position that medicalizing aging would not mean medicalizing life if one could control aging so that it was no longer taking place and life could exist without aging. However, controlling aging would only be possible under a regime of a continuous preventive medical control of the human organism. As there is no clear boundary between a fertilized egg or a newborn baby and an aging person – they are different aspects of the same temporal continuum – medical control of aging would likely start when life starts.

As a concept, disease denotes aspects of biological life that are deemed negative (dis-ease), not the whole of life, or its positive aspects (ease). If one finds it necessary to medically control the whole biological life process in order to prevent disease and prolong life, one should clearly state that this is what one wants to do. One should acknowledge that disease cannot clearly be separated from life. However, it would still be nonsensical to define aging and, by extension, life as disease.

The doctor's doctors

Paranhos, Flávio R L
flavioparanhos@uol.com.br

When physicians become characters in works of fiction it is not uncommon to portray them with positive colors. This was not the case, though, of the physician who also happened to be a brilliant writer - Anton Chekhov.

Chekhov frequently used physicians as characters in his plays and short stories. Interestingly, he did not seem particularly protective of these characters. His fictional colleagues are far from noble. In the short story *Ward No.6* Andriei Iefimitch is an extremely depressed doctor who despises almost everyone around him, except a patient in the ward for the mentally ill, who he considers the only intelligent person in town. Dr. Iefimitch ends up as an intern himself in the same ward, by the hands of his cynical colleagues. Astrov, the doctor in the play *Uncle Vanya*, is a bitter man who "doesn't love anyone" and is only capable of caring for the trees of the forest in his land. He is also a drunk and his love for the forest fades away when he encounters a beautiful lady. Despite the fact of being the only one with sensibility to perceive a young artist's talent, Yevgeny Dorn, the doctor in *The Seagull*, is a frivolous and cynical old man, who reacts to someone's angst about death dismissing it as "just an animal emotion". When Andrey tells Dr. Chebutykin in *The Three Sisters* that not only duels were immoral, but also being a doctor at one, he replies: "What difference does anything make?".

Chekhov's doctors give doctors (and medical students) a unique opportunity for an anti-narcissistic experience which can be used as a *pharmakon* in a catharsis, as proposed by Solbakk (Movements and Movies in Bioethics: The Use of Theater and Cinema in Teaching Bioethics, ten Have H. (ed). *Bioethics Education in a Global Perspective*, Springer, 2015). The result, however, is not purification, but a healthy anxiety.

A course on Medical Humanities in Padua: a method to encompass the ethical values of the arts in the field of medicine

Pegoraro, Renzo; Caenazzo, Luciana
renzo.pegoraro@fondazionelanza.it

Medical humanities encompass the idea of offering cultural and cognitive tools to health practioners allowing them to establish a "more human" and trusting relationship with the patients and their illness. The effort of "re-humanizing" medical education and practice emphasizes the concepts of human vulnerability, individual autonomy, empathy, and responsibility for the others as part of the basic identity of human beings. Instead of finding a clinical explanation, the humanities offer a deeper understanding of the human side of illness, both personal and social, encouraging a greater empathic understanding of self, the other, and the overall therapeutic process.

The Fondazione Lanza - Center of Advanced Studies in Ethics and Bioethics - organized a Summer Course in Medical Humanities in Padova (Italy). The course proposed an integrated and interdisciplinary approach to analyze and interpret the human experience of illness, disability, health care, and medical intervention in order to bring healthcare practice back to its original purpose: “to be a medicine for the person”. In order to clarify the ethical values represented by the arts in the field of medicine, the Fondazione Lanza’s course was structured with morning lectures followed by afternoon visits to important artistic and historical sites of the city. Through these activities, young medical students, physicians, and health practioners can initiate a personal reflective itinerary on the theme of pain and suffering. They can learn through the patient’s subiectivity to recognize the fundamental questions of life and death, right or wrong, good or evil, and find empathy as the guiding star of their profession of service.

Italian and international experts in painting, sculpture, literature, cinema, forensic science, psychiatry, bioethics, and history of medicine offered their qualified lectures, proposing a “humanistic” reflection on illness, medicine, the role of physicians and nurses. All contributions were intended to overcome a reductive notion of medical practices that explain illness only according to bio-molecular reactions. The humanities have always offered a fundamental contribution to the aspiration of gaining a more complete picture of illness, improving medical care and our assistance to the sick. Results of the course including contents and methods, and the participants’ evaluation, will be reported on, and authors will describe the structure of the training programme and discuss advantages and drawbacks of the course.

Medical Humanities in the Making: The Lasting Contributions of William Osler (1849-1919) to Medical Education and Practice

Pouliot, Francois
francois.pouliot@chudequebec.ca

Background and Central Ethical Issue: The year 2019 will mark the 100th anniversary of the departure of William Osler, maybe the most famous physician of his time, and a lasting influential figure in medical education. His textbook *The Principles and Practice of Medicine* was used by many generations of medical students before high-tech-medicine took over. His many essays, especially the short one *Aequanimitas*, are still an inspiration for new generations during medical school. His figure and his writings altogether are now, so to say, part of the medical humanities. Is there any explanation?

Arguments: The humanistic tradition represented during the Renaissance by Erasmus or Pico della Mirandola revisited the greek and latin authors in search of science, wisdom and freedom. Their search took an anthropocentric turn, struggling oftentimes against civil and religious authorities. In a similar manner Osler is considered nowadays as the herald of a more humane approach trying to counterbalance science and technology in modern medicine. Osler insists also on a long and diverse formation for physicians: the all-important matter is to get breadth of view as early as possible and resist the temptation to become a narrow-minded specialist. Finally, his person offers an exceptional role model, deeply rooted in spirituality and stoic philosophy, whose behavior and success can be emulated by younger generations.

Conclusion: In one of his numerous aphorisms, Osler stated that the humanities are like the hormones, influencing and soothing everything they permeate. They helped him to face “the uncertainty which pertains not alone to our science and arts but to the very hopes and fears which make us men. In seeking absolute truth, we aim at the unattainable, and must be content with finding broken portions”.

ICU nursing professional values system - Croatian qualitative analysis

Premuz, Hrvoje; Borovecki, Ana; Gastmans, Chris
hrwojeprem@gmail.com

Ethical and professional values of nurses are a part the professional healthcare environment. It is necessary to analyze them from different disciplines: nursing, ethics, philosophy, theology, social sciences. Societal circumstances and changes can have an impact on the professional development of healthcare workers and the quality of healthcare services. Professional value system (of physicians and nurses) has an immediate impact on all processes of healthcare delivery and their numerous outcomes. The aim of this study is to analyze existing professional value system in everyday work of nurses in intensive care units in Croatia.

Traditional values of nursing care like categories of compassion, caring and tenderness had a central place in nursing history, but in the context of contemporary technologically set medicine and health care systems are challenged as never before in an almost century-old development of professional nursing. Advancement in technology and centuries of science lead to social progress. The connection of science and technology culminates today while overflowing numerous ethical problems arise as a result of this process, in which the technical reason as a source of power for interest groups is set on a pedestal of social and civilizational prestige. The projection of these trends through a contemporary model of health care as a dominating factor in the development of healthcare systems directly affects the appearance of the clinical reality in which the action of nurses is an indispensable part

A focus group research with the aim of defining the basic set of values of professional value system among nurses working in intensive care units in hospitals in Croatia will be presented. The research question was: Is there any significant differences among ICU nurses in Croatian hospitals due to the professional value system of nurses which are set on three levels of education, assistant nurse, bachelor and Master of Nursing

Three focus groups were held each composed of 12 respondents nurses from intensive care in Croatian hospitals. Groups was standardized according to the demographic structure of nurses in Croatia for a certain educational level (the geographic distribution, age and gender). The first focus group was composed of under graduated nurses' assistants (nursing secondary school – specific for Croatian educational system), the second group was composed of baccalaureates of nursing, and the third group will be composed of nurses with a diploma or degree of

The results of this Inquiry show significant differences in a value statements and attitudes among ICU nurses in Croatia.

Karl Jaspers and the relevance of teaching humanities to psychiatrists

Quintin, Jacques
Jacques.quintin@usherbrooke.ca

The psychiatrist and philosopher Karl Jaspers underlined the need to develop empathy for a better understanding of the lived experience of people suffering mental health issues. He used the thought of Dilthey who opposed the sciences of nature and the human sciences, the latter consisting in understanding the human life from an interior perspective. But how can we really get inside the story and history of other people? Is it possible to educate doctors to improve their understanding of the lived experience of sick people? The most important issue is to ask if it is possible to attain human self-consciousness and self-accomplishment without linking up existential questions pertaining to the human condition. In this way, humanities can be useful for a better understanding of what escapes the conceptual thinking, which always thinks according to categories. The advantages of humanities do not consist in understanding what reality is or being in itself, but to understand the meaning of experience "als ob", "comme si", i.e. through metaphor. Humanities are a field of study involved in the quest for meaning, an opportunity to step outside of specialized studies and to reflect things from a different perspective. But a better understanding is not enough. Humanities allow health care professionals to give an opportunity to people to express themselves, so their voices do not fall silent. As Jaspers said, humanities give “a humanly oriented attitude… in recognizing human dignity”, so a human being is more than an object for a diagnosis. In this case, the argument that humanities are not valued because of a lack of time and resources is no more acceptable.

Feelings of burden in palliative care

Rakic, Milenko; Escher, Monica, Elger, Bernice; Eckstein, Sandra; Pacurari, Nadia; Zwahlen, Susanne; Wienand, Isabelle
milenko.rakic@unibas.ch

Our study focused upon feelings of burden of palliative care patients, their families and friends. We analysed 300 medical records of palliative care patients cared for at three Swiss university hospitals using content analysis. Most patients had a cancer diagnosis. Mean age was 67.6 years (range 22 to 98 years). Burden and overburden were identified as main categories. They were further divided into the following sub-categories: burden for patients and burden for families and friends. Patients often felt burdened by disease, financial problems, and families’ reactions to disease. A reason for patients to feel overburdened was their own disease. Families often felt burdened because of issues related to patients’ medical condition. Moreover, families mentioned homecare and the decision-making process as a burden or overburden. We suggest that the feeling of burden should be better addressed in order to 1) alleviate, when possible, the exhausting tasks of patients and their families and 2) to promote patients’ autonomy and their families’. Indeed, the respect of patients’ autonomy goes hand in hand with the respect of their family’s and friends’ who – in the case of families – very frequently act as informal caregivers. In our analysis of burden, we suggest that we should consider the patient as part of a larger network of relations and be sensitive to the self-determination and well-being of the persons (particularly the informal caregivers) involved with the patient. Health care professionals should be aware of the beneficial aspects of this enlarged notion of patient’s autonomy in order to better address the feelings of burden and overburden.

Posthumous assisted reproduction: Should we also allow parents to use a deceased’s gametes?

Ram-Tiktin, Efrat
Efrat.ram-tiktin@biu.ac.il

This paper addresses the ethical aspects of use of a deceased's gametes by his parents in order for them to become the offspring’s social parents or grandparents. Posthumous assisted reproduction is currently acceptable in a number of countries. The ASRM and the ESHRE ethics committees have provided justification for the spouse’s use of a deceased's gametes or embryo if the deceased left written consent. Although the ESHRE mentions that the use of the deceased's gametes by a third party is acceptable if written consent was given prior to death, the possible complications have not been addressed and this paper will attempt to do so. More specifically, I will address three possible scenarios (all of which have been discussed in Israeli courts). In the first, the deceased’s parents wish to become the offspring's social parents (using egg donation and surrogacy). In the second and third, the deceased’s parents wish to become the offspring's grandparents through collaboration with a future mother. This case is discussed for two possibilities: a. The deceased had a partner before his death but she refuses to use his gametes or to let other parties make use of them. b. The partner does not wish to use the gametes but does not object to their use by a third party.

In discussing these cases, the following questions will be addressed: First, what moral weight should be given to the deceased's wishes regarding the use of his gametes after his death? Second, do the wishes of the deceased's partner outweigh those of the deceased's parents? Third, under what circumstances and on what grounds can society approve or limit a third party's use of a deceased's gametes?

What's wrong with gene editing? Probably many things, but…

Raposo, Vera Lúcia
vera@fd.uc.pt

Genetic engineering has been a repeated topic of reflection among scientists, ethicists and lawyers in the last decades, but until recently its low levels of success labelled it as science fiction story. However, recent events related with the development of gene editing (a more precise method of genetic engineering), namely CRISPR-CAS9, changed our perception, turning it in a promise that may become effective in the next couple of years.

The new technique CRISPR-CAS9 can find a specific location in the genome in which to intervene, in a simpler and less expensive way than in the past, and also with a much lower probability of mistakes. So, if successfully developed it has the potential to change, not only the genome of a single individual, but also of future generations in a safe and efficient way. Although the scientific community asked for a moratorium regarding CRISPR-CAS9, the fact is that the UK allowed investigation with this technique in embryos for research purposes, so, the future is merely waiting.

Arguments frequently invoked against gene editing include the principle of human dignity, the prohibition of discrimination and Article 13 of the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (Oviedo Convention). Critics target in particular the changes operated in the genome of future generations (germinal genetic interventions) and changes aimed to human enhancement. It seems that the only interventions eventually to be allowed are somatic intervention for therapeutic purposes.

However, none of these arguments make a definitive case against gene editing, not even against its broader range. In effect, it remains to be demonstrated how can human dignity be undermined by genetic interventions, a demonstration that would require a previous clarification of the meaning given to human dignity for this purpose, lacking until now. Human dignity does not equate to genetic immutability nor our "God given" genome is more dignified than a modified one. On the other hand, to argue that it would create inequalities is to forget the various social, economic and educational discrepancies existing in our society, putting all the blame on genetic interventions and reducing the person to his/her genes. Further, this reasoning omits the profound genetic inequalities between our "genetic gifts" (some may call it "genetic luck") and disregards how can gene editing equalize them, thus creating a new genetic equality. As for Article 13 of the Oviedo Convention, it should be noted that the distinction therein accepted between therapeutic and non-therapeutic interventions is far from clear and thus insufficient to base any legal solution.

I don't intent to sustain that all types of gene editing should be accepted without further discussion. But I certainly want to demonstrate that the arguments invoked until now against it are not self-justifying not are they enough to impose a legal ban on gene editing.

Ethical work post trauma

Rehmann-Sutter Christoph
rehmann@imgwf.uni-luebeck.de

A 'trauma' in the psychological sense of the term, is a psychic injury. It can lead to severe stress and mental suffering, which have been recognized as a psychiatric condition since DSM-III under the title of ‘post-traumatic stress disorder’ (PTSD). In addition to individual burden and moral conflict, both actual and in retrospective, which pose serious moral questions both for the individual and for others, the existence of trauma also can create difficult and conflicting situations in society. Not all the difficult things that have been experienced can be addressed by language. There are impediments, some soft, others hard, or impossible to overcome. Victims become silent.[1] There are social constraints, which make acts by former perpetrators literally undiscussable.

On the basis of Dan Bar-On’s distinction between what is ‘indescribable’ and what is ‘undiscussable’ and referring to the concept of ‘collective trauma’, I will identify and try to clarify some ethical questions connected to the impossibility to narrate traumatic experiences. How can ethical work from the perspective ‘post trauma’ address past acts and experiences (atrocities, extreme violence) that cannot, or can only partially be narrated? I will argue that there is an important role of art to create a space of reflection. I will use one exceptional film as an example: *In the Crosswind*, directed by Martti Helde, Estland 2014. This film is composed of a series of *tableaux vivants* and tells a story through acted stills. The viewer becomes part of the story that is told in the film and participates in its moral work.

[1] The last lines from Wilfred Owen’s poem, The Send-off, written in World War 1: “A few, a few, too few for drums and yells, / May creep back, silent, to still village wells / Up half-known roads.”

Impossible moral requirements, ancillary care responsibilities and moral luck in health research

Rennie, Stuart
stuart_rennie@med.unc.edu

Health researchers, particularly in resource-constrained settings, sometimes feel trapped in unfortunate circumstances where they have a moral obligation to provide medical care for research participants, but which (for various reasons) they cannot fulfil (Thomson, Ansoms and Murison [eds.] 2013) They experience themselves as ending up, at least partly by luck, doing wrong; depending on the gravity of the medical needs, it could be substantive wrong. This *prima facie* tragic and heartrending situation constitutes a convergence of three major topics in moral philosophy and research ethics: (1) whether there are genuine moral dilemmas, i.e. situations where moral wrongdoing is unavoidable; (2) whether (and if so, why and to what extent) ancillary care is owed to research participants; (3) whether (and if so, why and to what extent) one can be legitimately held responsible for what is beyond one's control.

Given how distressing such a situation would be, it is tempting (at least for philosophers) to argue a way out. One could argue that, on closer inspection, there are moral conflicts, but no genuine moral dilemmas. One could defend the claim that the scope and strength of ancillary responsibilities towards research participants by researchers are (or ought to be) very limited. And even if people are sometimes held (and hold themselves) responsible for what is due to luck, one could reason that it is generally unfair and/or irrational of them to do so.

However, there are reasons to think such situations really do exist. Tessman (2017) argues that in a subset of moral conflicts, particularly ones where much of value is at stake, the moral demand of an obligation is not cancelled out by the fact that it is impossible to fulfil. Richardson (2012) argues that when doing health research, researchers become morally entangled with their participants through interactions in which the latter surrender some of their privacy to the former. This forms a normative basis for (in a range of cases) providing medical care to research participants that is not required to make a study scientifically valid, to ensure a study's safety, or to redress research injuries (Richardson and Belsky 2004). Moral luck, as not necessarily unfair and irrational, also has its defenders (Hartman 2017).

The goal of this paper is not to examine in detail the merits of the philosophical positions on these three vast topics. It is rather to explore further questions: assuming that health researchers really can find themselves in these dire predicaments, is there an obligation to minimize this from happening? If so, whose obligation is it? How, short of avoiding doing research in resource-constrained settings altogether, can the prevalence of such situations be reduced? If such situations are unlikely to be eradicated altogether, what makes that the case?

The “Found Bioethics Text” (FBT) — Public Communications Media as Fields of Bioethics Inquiry, Analysis and Pedagogy

Robeson, Richard
robesor@wfu.edu

One of the most significant demands of introductory-level bioethics pedagogy, particularly at the undergraduate level, is to remind (or persuade) students that bioethics inquiry and analysis are invited by most aspects of everyday life, not just within the academy or within particular healthcare or research settings. One strategy for achieving this is the use of the “found bioethics text” (FBT) — a personal neologism that identifies content from various media which, though not necessarily intended to serve a function of bioethics inquiry or analysis, is nonetheless useful as such. If, as American bioethics scholar Tod Chambers posits in a discussion of the significance of narrative in bioethics, “cases are stories” (“Literature,” *Methods in Medical Ethics*, Ed. Sugarman & Sulmasy, Georgetown University Press 2010), then the obverse — stories are cases — is equally true. FBT is an opportunity to recognize a bioethics narrative, perhaps even an unintentional one, that can exist in as little as a single image in, for example, an airline magazine.

This paper describes the use of print, electronic (television) and digital (internet) advertisements for matters ranging from recruitment for participation in clinical research, to healthcare services (from conventional to “alternative”), to commercial DNA analysis companies (e.g. 23andMe, Ancestry.com), as means of teaching undergraduate Communication majors to identify and interrogate bioethics issues. Further, the resulting analyses were disseminated via a concurrently developed digital medium termed Bioethics Radio, which in turn exploits the broad availability and extremely low cost of modern digital audio software and hardware to produce high quality programming devoted exclusively to bioethics, for online consumption within the university community and beyond.

The examination of FBTs thus serve two purposes: encouraging Communication students’ alertness to the presence of bioethics-relevant issues in their commonplace engagement with the plethora of contemporary media entities; and advancing the concept to students, and others, that internet radio (streaming, podcast, etc.) can be fairly regarded in this context as one of the medical humanities.

The discussion will also address the challenge of simultaneously teaching (1) bioethics theory, and (2) audio recording and production techniques. Case examples include not only students’ lines of inquiry into particular FBTs (text versions of audio recordings), but also accounts of the in-class discussions that followed students hearing each other’s work.

Additionally, in proposing Bioethics Radio as a model for an innovative approach to bioethics pedagogy, the paper will also discuss the criteria by which the students’ work was evaluated.

Posthumous interests and the ethics of research on the dead

Rozynska, Joanna
jrozynska@gmail.com

The use of cadavers and cadaveric specimen in research, particularly in biomechanical and biomedical research, presents many scientific and social benefits. But it also raises numerous ethical and legal questions. Majority of international and European standards for conducting research on biological material of human origin stress the importance of respecting the dignity, autonomy, privacy and confidentiality of donors, living and deceased (see for example the WMA Declaration of Taipei on Ethical Considerations Regarding Health Databases and Biobanks, 2016, par. 6 & 9). Both in regulatory documents and bioethics, special attention has been given to the consent or other form of authorization for the removal, storage, and use of the cadaveric biological material for research (see for example, Recommendation CM/Rec (2016)6 of the Committee of Ministers to member States on research on biological materials of human origin, article 14). However, relatively little has been said on the nature of interests of the deceased donors that are protected by these regulatory requirements.

In this paper I will discuss the concept of posthumous interests and its significance for the ethics of conducting research on cadaveric biological material. First, I will present the idea of posthumous interests, and I will outline the main arguments for and against it. Next, I will analyze types of interests that are often considered to be able to "survive" death – what is their content; how they are related to the analogous ante-mortem interests of the living person; what is their "ethical power". Finally, I will critically analyze an argument that integrity, privacy, and reputation are prime candidates for posthumous interests that are of moral relevance for the practice of cadaveric research.

Normative and descriptive aspects of diagnostic reasoning proposed in evidence-based medicine with its consequences on clinician/patient communication

Rutkiewicz, Wojciech
rutkiewicz.w@gmail.com

Medicine is a realm where clinicians make tough decisions under huge uncertainty. Knowledge is a key factor to patients' wellbeing in a clinical process. Physicians gain knowledge from results of randomized controlled trials published in scientific articles and from clinical interview with patient. Patients, however gain knowledge directly from a physician. This reciprocal exchange of information requires efficiency in communication between clinician and his patient. But this is only one of two conditions for successful clinical process. Another one requires from physician advanced computational skills in order to process great amount of clinical data.

When we are ill we expect that we will get professional care from reliable physician. We take it for granted and this belief comes from scientific character of medicine. Enlightenment and works of such minds as Xavier Bichat, Rene Laënnec or Hermann Boerhaave started process of making medicine more and more scientific. Its important phase is the year 1990 when term "evidence-based medicine" (EBM) first time appeared in medical literature. Centuries of medical research provide knowledge that physicians can use till today. Now the most reliable source of knowledge is randomized controlled trial. Thanks to EBM it becomes the gold standard of medical methodology. Alongside developing methods of knowledge acquisition EBM also provides a method for application this knowledge to clinical practice. That is why EBM has formulated four steps for physicians' practice: 1) formulate clinical question, 2) search medical literature for relevant evidence, 3) critically evaluate evidence, 4) implement useful findings to your practice. However, this still does not explain how clinicians actually transform general medical knowledge to knowledge about individual patient. In fact, this raises a question about the way clinician thinks within his practice.

In my presentation I would like to show what are EBM's guidelines for medical thinking. It is focused on Bayes Theorem which usage requires special skills from EBM practitioner. Medical technology such as computer-assisted diagnosis helps clinicians, however a multiple of researches point that the problem lies within implementation Theorem into clinical practice. This situation creates a gap between normative and descriptive aspects of diagnostic reasoning. Statistical thinking with Bayes Theorem belong to the normative aspect. Descriptive aspect includes heuristics. First, I will present two kinds of interpretations of the term "heuristic" in reference to medical realm. Second, I would like to show consequences of limiting the usage of statistical thinking in diagnostic reasoning. Third, I will present pros and cons of using heuristics by clinician and significance of proper communication between physician and patient.

Incidental or secondary findings in genetics: stairways to a life of certainty?

Saelaert, Marlies
Marlies.Saelaert@ugent.be

Since science started to unravel the human genome, the idea has risen that we are discovering the building blocks and the blueprint of life. Physical qualities, health and illness and even character traits turned out not to be determined by accident or fate, but to be the result of a constant interaction between behavior, environmental factors and very specifically organized DNA strands. As genetic knowledge still increases at high speed and more genes and their function get revealed, the human possibilities for action and prevention, also on the level of healthcare, keep on growing. In some cases, illness can even be prevented, which might create the impression of a predictable health trajectory.

If, despite this promising evolution, illness strikes, patients' questions are tried to be answered as good as possible, i.a. by use of genetic testing. Over the last few years, the technology of Next Generation Sequencing (NGS), by means of which the whole exome or genome is analyzed, has been introduced in the diagnostic context and it is most likely that NGS's application as a diagnostic tool will only increase in the future. However, NGS might not only answer the initial questions but it might also reveal additional information and (initially) unsought-for health risks, as incidental or secondary findings (ISFs).

According to the (currently utopian) dream of a perfectly predictable future, genomic information seems to be a valuable tool. This genetic knowledge might raise the idea that it will be possible to predict which illness one will get, at what time the first symptoms will appear, and which prevention or treatment will be most effective. ISFs can stimulate this feeling of knowledge and control, as they might offer an extra chance to avoid serious morbidity or to prepare for future health evolutions.

However, one might wonder if this feeling of certainty and control is legitimate and whether the utopian dream can ever be realized. Currently, scientific knowledge is lacking on many genes' function and on the actual pathogenicity of many variants. Moreover, due to incomplete penetrance and variable expression, pathogenic variants do not indicate a delineated truth but a wide spectrum of possible futures, while also many environmental factors can influence the final outcome. Therefore, ISFs might not only be a way towards certainty and security but also towards doubts, uncertain knowledge, hesitation and worries.

To realize a better understanding of the status of ISFs, we have set up a qualitative study and we have been interviewing patients with a Mendelian disease about their experience with NGS and the meaning they ascribe to ISFs. In our presentation, we will focus on patients' ideas regarding the possible knowledge of additional genetic predispositions. How is this information perceived as contributing to a feeling of certainty? Are ISFs hidden stairways to control? Or will patients get off-road, confused by the many possible ways to go?

Ethics of Palliative Sedation

Sahm, Stephan
stephan.sahm@t-online.de

The World Medical Association has recently started a debate about issues of medical care at the end of life. Five regional conferences have taken place in all continents. Only during the

European meeting there had been controversial discussion about euthanasia and assisted suicide while in other parts of the world such practices have been rejected.
To offer competent palliative care is crucial as one of the arguments presented by those who endorse life ending acts is to alleviate suffering. The majority of symptoms are to be dealt with using modern palliative care. Yet, there remains a group of patients in whom symptom relief will not be achieved adequately. In those cases, palliative sedation is offered as an alternative.
The ethics of palliative sedation needs clarification. Problems arise with respect to delimitation from intended life ending acts such as euthanasia and assisted suicide. In this paper it is argued that palliative sedation is i: reversible and, ii: to be confined from deep sedation until death. Hence, palliative sedation is morally different from intending to end patients´ life which is the case in killing on demand and assistance with suicide. The account presented is based on reflections about the hermeneutics of suffering, conceptions of medical acts at the end of life and the goals of medicine.

The powerful placebo? How placebos display the human condition stretched between medicine, arts and the humanities

Sauder, Michael
michaelwsauder@gmail.com

Investigating what is involved in administering a placebo sheds light on what is involved in all interactions in clinical medicine. First, although we still refer to the art of healing, medicine is now seen primarily as a science. Certainly, if science consists of systematic investigation of our world, medicine is such. But the goal of medicine is not merely knowledge acquisition, but the healing of humans. Thus medicine is an applied science. Moreover, this healing must be accomplished not only by application of carefully curated chemicals, but by the action of a person, a healer. Understanding medicine thus involves investigating what doctors do in a therapeutic interaction, not only what they prescribe. Then there’s the patient, who listens, evaluates, and even sometimes follows the doctor’s advice. So comprehending a patient’s healing also requires paying close attention to what patients think, believe and expect, not only what they swallow. I argue that this is the same attention that is required to understand placebos, because placebos are also stretched between medicine, arts and the humanities. Placebos were first thought of as a harmless method or medicine which has some power, although it pleases rather than cures. But in the 20th century definitions have focused on a placebo as an inert substance with no power, thus used only in research, or by a charlatan. So are placebos powerful, or powerless? This paper will mediate this dispute, using the framework above. First, we must correct the most common error in thinking about placebo interventions: we must shift focus away from the placebo as a substance itself, to the beliefs and expectations of the people involved when a placebo us used. To decide if something is a placebo, we must consider the doctor’s beliefs about its efficacy, the patient’s beliefs about the doctor’s beliefs, and the patient’s belief about the intervention’s efficacy. The doctor must think that using a placebo will not be causally related to improving the patient’s diagnosed problem, but may still help, by pleasing or satisfying expectations. But the patient must think the doctor thinks it will help specifically the patient’s diagnosed problem. And the patient must himself believe that it can do so. Patients can improve after placebo interventions. This does not mean an ineffective pill has had an effect. Rather, remember that any pill or procedure is administered in a context, involving an encounter between people who must have beliefs and expectations. Why not allow that these contextual features can be causally powerful? If so, can we harness these powerful contextual features to strengthen all clinical interactions? Yes, because the placebo in use is a microcosm of the human condition, stretched between medicine (which leads us to focus on chemical composition of a pill), the art of the healer (who presents an intervention in a particular context), and the humanity of a patient who interprets, responds, and sometimes swallows.

Will the circle be unbroken? Movies as seismographs for the desire to plan death individually on the ICU

Schmidt, Kurt W
ZEMmarkus@aol.com

For over 50 years, TV series and movies have been granting us insights into state-of-the-art intensive care medicine. Even though they are not documentaries, many TV series, such as *Emergency Room* (USA 1994-2014), *Casualty* (GB 1986-) or *Cardiac Arrest* (GB 1994-1996) make an effort to portray ethical conflicts, decision-making processes and medical interventions realistically. In the case of reanimation (CPR), however, the rate of successfully performed measures in American hospital series is much too high compared with the reality. And in British hospital series, the people who are reanimated are on average much younger and healthier than in the clinical routine. This arouses false expectations in audiences regarding the outcome of CPR, and the question arises of what impact this has on the drawing up of a living will (Do you wish to be reanimated: yes/no?). Films often exaggerate the outcome, choose not to show the sometimes severe neurological side-effects, and fail to include any kind of ethical consultation. Witzel et al. (NeuroGeratrie 2008) investigated the influence of TV on anxiety prior to surgery and discovered that patients who often watch hospital series are more worried about going into hospital and less satisfied with the ward rounds! In movies operations tend to be fraught with complications (to increase the drama), while in TV series hospital staff take more time to talk to their patients.

Nevertheless, movies pick up on patient hopes and expectations which should be taken seriously in conjunction with clinical routines. One example is the wish to profit from high-tech intensive care medicine on the one hand, but then on the other hand, if survival with a certain level of quality of life is no longer achievable, to have the possibility to plan the dying process individually. This does not mean "physician-assisted suicide" (PAS), but to have some say in the way one's life should come to an end. With the help of two examples, the talk will show how movies and TV series can be used during further training events in hospitals to address the issue of individualized death (also on the ICU).

Visualization strategies in forensic imaging & Virtopsy: recommendations based on semiotic analysis

Schweitzer, Wolf; Thali, Michael; Aldmoar, Eloisa
wolf.schweitzer@irm.uzh.ch

Virtopsy is a post-mortem forensic imaging approach mainly based on full body CT (computed tomography). The process has become routine and we build on extensive experience with using these images for written documentation and in court.

This paper focuses on how these 3D renderings subconsciously and consciously achieve a specific cultural connotation and gain or lose epistemic value through details that the user can change. CT is based on X-rays and not real light, and 3D-renderings are created from the data with artificial illumination and colors. The work step that creates 3D-renderings inside CT reading software typically is defined by software presets that the user can modify. Hardly any user actually modifies these, and so standard factory presets issued by the software manufacturer so far dominated visual reality in post mortem forensic imaging. All the same, the images did not appear as competent or convincing as the data quality would justify.

A collaboration with the Zurich University of design was sought. We varied the 3D presets and performed an extensive semiotic analysis of hundreds of widely varied 3D images that were created from post-mortem CT. Cooperating with the arts turned out to be eminently beneficial for forensic imaging.

Historically, the development of 3D visualization software has led programmers to prefer specular reflections (surface reflections that create a shiny "chromed" appearance). They also tend to prefer vibrant colorful appearances. In extreme instances, a skull may be rendered shiny and golden, which may convey a connotation of a pirate movie. There are technical explanations for that: when 3D renderings were introduced, giving a reader so-called depth cues was achieved using specular reflections and colors. These features are still presented with great pride in the computer visualization community.

The forensic user works in a different culture. There, too much color and specular reflection represent sometimes subtle but often irritating distractions which may also reduce credibility in the material presented. There, a 3D rendering should not look shiny, wet, or vibrantly colorful. Forensic users need images to specifically inform bereaved, judicial authorities, courts, forensic scientists and defense lawyers. That requires a different visual approach.

A previously possibly unreflected usage of 3D visualization presets that derive from a computer programming culture may have been a significant reason behind the often subtle, sometimes overt critique within the forensic field, where post mortem CT scanning per se was attacked, not the single step of visualizing data. We subsequently used visual 3D appearances perfectly tuned to a forensic audience and found that the discourse – also with state attorneys or defense lawyers - has perceptibly improved, with a new focus on actual findings and content interpretation.

To sum up, collaborating with the arts in the field of scientific visualization not only proved to result in better images for forensic post mortem CT applications, but also stimulated the reflection of epistemic issues which can be traced back to visualization cultures that differ across industries that are underlying a communication culture.

Bioethics and popular culture

Scott, Niall
nwrscott@uclan.ac.uk

This paper looks at developing a methodology for the study of bioethics and popular culture. It is not uncommon or bioethical issues to be explored through the lens of popular culture- through literature, cinema, musical performance and gaming culture to name but a few methods. However, such explorations tend to use popular culture as a springboard to illustrate certain issues (often superficially) rather than investigate any deeper relationship between bioethics and popular culture itself in the sense of and interactive effect between the two areas. Instead, I am interested in what impact a pop cultural gaze can have on bioethics. In other words, are there certain areas of bioethics that are or could be affected by the various ways the human body is represented in popular culture? For example, does body modification and genetic enhancement as represented through popular culture in say, science fiction cinema have the potential for affecting bioethical concerns regarding such modifications and perspectives on the human body in practice? If popular culture is a "site where meanings are contested and where dominant ideologies can be disturbed" (Gammon, L. and Marchmont, M. 1989, 1), can such a view this lend itself to a disruptive study of a bioethics *of* popular culture rather than the merely illustrative use of bioethics *and/in* popular culture?

Getting what you want: the case of genetic relatedness in the context of assisted reproduction

Segers, Seppe
Seppe.Segers@ugent.be

The goal of having genetically related offspring is often described as a ‘fundamental human need’ or as a ‘natural drive’. This is not a merely descriptive assertion. It is much rather performative, in the sense that it is invoked to justify moral obligations to accommodate this goal of genetic parenthood in the field of assisted reproduction. Such assumptions, however, require normative interrogation. That there may be ‘evolutionary reasons’ for this presumed drive does neither justify that it should be met, nor does it mean that it cannot be overcome. More: the contextual reality is that in the field of assisted reproduction, attempts to reach this goal are not free of other interests that have to be taken into account (e.g. the future child’s wellbeing but also broader community interests). This leads to a complex balancing of interests, to which the normative importance of the goal of genetic parenthood is central. For one thing, even if many people highly value having a genetically related child and are willing to accept certain risks and costs to others to obtain this, such an observation does not in itself entail the normative conclusion that one should accommodate this desire. In this presentation, I will provide a novel framework to analyze the normative significance of this desire for genetically related offspring, in order to assess how far one should go to accommodate this desire. This is especially relevant for the ethics of assisted reproduction. The presented argument will provide a ground to show that there may be a pro tanto moral obligation to accommodate the desire for a genetically related child, which means that its normative significance might be trumped by other considerations or moral norms in actual contexts. In doing so I will build on and bring together insights from theory of need, philosophy of desire and feminist ethics.

The relationship between music and medicine as evidenced in the medical literature

Shandera, Wayne X
shandera@bcm.edu

Background: The fields of medicine and music are philosophically and technically interwoven. The skills needed for each endeavor are both similar and different. They both require intelligence, discipline, memory, and empathy but differ in that music also demands stage performance and artistic sensitivity. This study assesses whether currently reported medical findings provide data on the overlap between the two disciplines.
Methods: The medical literature was searched for articles published between 2015 and 2017, articles that used the term “music” in their titles, using PubMed sources, excluding animal studies and limiting this to studies with abstracts. Titles were reviewed and categorized as therapeutics, pathophysiology, risks of listening to or excessively performing music, effects of music on health care providers, linguistic studies, music achievement in cochlear implants, and miscellaneous articles including interviews, historical studies, video and computer studies, and ethical studies.
Results: Among 633 articles in PubMed assessing music in the medical literature, the largest number, 246 (38.9%) dealt with the therapeutic aspects of medicine. Less common article topics included pathophysiology of musical activities in 137 (21.7%), other effects of medicine on man in 57 (9%), the hazards of music exposure in 27 (4.3%), and a comparison of language and musical skills in 24 (3.8%). Additional articles assessed the role of music with cochlear implants in 22 (3.5%) and the effects of music on health care providers, such as surgeons in the operating room, in 8 (1.2%). Articles dealing with therapy were most often concerned with

effects on anxiety in 79 (32%), on chronic pain in 38 (15%), on depression in 29 (12%) and on cognitive impairment in 28 (11%). Less frequent articles concerned effects on sleep in 6 (2%) and on autistic behavior in 4 (1.5%) among therapeutic trials. Results were generally positive in 186 reports (75.6%), negative in 16 (6.5%), mixed in 16 (6.5%) and inconclusive in 15 (6.6%). Standard statistical reporting was the exception in most articles. Among studies with salutary effects, those assessing cognitive impairment (96% pf 27 studies), sleep quality (100% of 6) and autism (100% of 4) reported the strongest responses to music therapy. Three articles dealt with ethics and medicine, including an application of the core of bioethical principles to the care of musicians by providers, a discussion of training in spiritual competency for musical therapists, and a review of the benefits of musical therapy for dementia patients.

Conclusion: The published literature provides insight into current interplay between medicine and music at the practical level. The medical literature reveals how increasingly music is being used for therapeutic purposes, especially with anxiety, chronic pain syndromes, cognitive impairment, insomnia, and depression, and in the rehabilitation of patients with cochlear implants. The salutary effect of music therapy, however, is not universally established; therefore, larger, more definitive studies are needed. In the area of ethics and music, there is a particularly strong need for additional studies.

Ethical dilemmas in humanitarian medicine: how best to prepare?

Simm, Kadri
Kadri.simm@ut.ee

The context of humanitarian disasters – often characterized by acute time-pressure, lack of resources, unfamiliarity of circumstances – is stressful for medical (as well as other) professionals. Stress has been shown to have a negative impact on decision-making capacity and consistency. Decisions need to be made but the ethical principles and practices of traditional clinical care might not always be helpful. Rather the opposite – these might constitute a source of distress as the applicability of individual-centered patient care or the home-country standard of care, becomes unclear. From the perspective of ethical regulation, humanitarian disasters can often be a site for clashing ethical frameworks. For example, principles governing clinical care vs those appropriate for public health concerns. Another potential minefield pertains to situations where research component is incorporated into the care that is being provided.

A successful preparatory training would contribute to better psychological coping and stronger resilience for returning healthcare staff. People would be better prepared and aware of the inevitable ethical challenges that arise in such contexts. In the long term this could also mean that more people are willing to continue with humanitarian aid work and levels of moral distress, widely understood, are kept under control.

What is the best way to achieve these results? It is clear that learning about professional codes, available decision-making tools and other relevant guidelines, frameworks and best practice guides is very important and often helpful. Yet, it has been recognized that these formal instruments might not be sufficient – applying the abstract principles in particular contexts is a skill that one often does not master by learning about theory. Also, such documents are generally not very useful in helping people to cope with the emotional stress that accompanies ethical challenges and the difficult choices that need to be made in disaster context. After all, you might have acted ethically correctly but you will still feel bad.

Furthermore, research by moral psychologists has demonstrated that moral decision-making tends not to be a type of rational reasoning built around the good and the bad (consequences, universalizability) but rather automatic, unconscious, quick decisions - “moral intuitions come first and directly cause moral judgements” (Haidt 2001:814). What follows from all this for the prospect of being successful in teaching ethics? I will illustrate how these different elements of moral reflection come together in a case-based approach that we have developed in University of Tartu Centre for Ethics.

Teaching Potti at the ‘Scene of the Crime’: Scholarly Misconduct, Transparency, and Learning Research Integrity from Case Studies You (Should) Own

Simon, Christian
christian.simon@duke.edu

There is concern internationally for the frequency of scholarly misconduct and the limited means of addressing misconduct. Actual cases of misconduct are typically a source of institutional embarrassment, and tend to be covered up locally, rather than scrutinized and debated. This approach is misguided, however, since institutions, faculty, and staff stand to benefit from constructive engagement with cases of misconduct that have occurred in their midst. An openness to such cases offers an opportunity to learn valuable lessons about scholarly integrity and the responsible conduct of research (RCR), and to “own,” address, and bring closure to cases that may have been highly damaging and traumatic to the local academic community.

In this paper, I consider an ongoing effort to learn from a costly and very damaging case of research misconduct, that of Anil Potti, M.D., which occurred at Duke University between 2009 and 2012. The case of Potti is relatively well known. It was widely reported in the U.S. media, including in 2012 on the American show, *60 Minutes*
(*https://www.youtube.com/watch?v=eV9dcAGaVU8).*

It has been analyzed in articles, books, and websites as another example of research, ambition, and institutional accountability gone awry. Since September 2017, I have participated in an initiative to train all research staff and faculty in the Duke School of Medicine in RCR and research integrity. This training was one of several steps taken to improve research integrity and the culture of research at Duke University. Others include changes to research oversight and compliance, student RCR education and training, mentorship and internship, technological innovation (e.g., open-science platforms, plagiarism detection), and policy improvement (e.g., added reassurances for whistleblowers).

In this paper, I provide a summary of the Anil Potti case and how it is being approached to improve RCR training and learning in the School of Medicine at Duke University. I discuss some of the legal, political, and cultural challenges experienced in this effort. The goal of the paper is to demonstrate how a misconduct case can be introduced to faculty and staff at the institution where the case occurred, what kinds of issues and concerns may need to be addressed when doing so, and what benefits this process may have in the mission to enhance the RCR and research integrity at a given institution. Clearly, the Potti case and Duke University itself are unique in a number of respects, and lessons learnt here will not necessarily transfer neatly to other cases and places. Nonetheless, both the Potti case and Duke University have much in common with other misconduct cases and academic research centers respectively, and I aim to point out some of these commonalities in order to strengthen the paper’s relevance and usefulness for other centers. Insights from Duke’s experience with the use of a local misconduct case as a teaching and learning resource, as well as a means to demonstrate transparency and ‘ownership’ of the case, may prove useful for academic institutions, educators of RCR, and other stakeholders in RCR programs and initiatives.

Self-expression through typing (SETT). Is SETT a valid method of meaningful communication for minimally verbal autistic people?

Simonstein, Frida
fridas@yvc.ac.il

In the autistic spectrum disorders (ASD) non-speaking autistics represent the most challenging category. The present research aims to contribute to the improvement of the understanding, diagnosis and treatment of minimally verbal autistic people. The aim of this research is to demonstrate that Self-expression through typing (SETT), learning to point autonomously at the alphabet to communicate, not only words, but also thoughts and ideas, is a valid method of communication for non-speaking and minimally verbal autistic children and adolescents.

SETT could be learnt and circulated for the betterment of non-speaking autistic people, their families and caretakers; and become part of the regular curriculum in schools. The importance of this research is that meaningful communication with SETT may become a useful channel to unveil the huge enigma posed by autism, particularly among non-verbal autistics. If SETT is validated as a universal intervention for non-verbal and minimally verbal autistic people, the whole concept of ASD would have to be reevaluated, as well as the diagnostics for autism, present treatments and policies, especially toward the non-verbal sector of the spectrum.

The end of human reproduction

Smajdor, Anna
anna.smajdor@ifikk.uio.no

Humans are one of the biggest success stories on the planet. They have colonised the globe and wiped out swathes of their competitors and predecessors as well as vast numbers of co-existing species. But according to the pessimistic Norwegian philosopher Peter Zapffe, the very attribute in which we take most pride is at odds with life itself. In this paper, I explore Zapffe's ideas as expounded in his essay The Last Messiah.[1,2] In particular, I want to show how his thoughts on mankind's predicament can illuminate some current questions about the trajectory of human reproduction.

Zapffe argues that human consciousness exposes us to the brutal meaninglessness of our existence. We cannot live with such harsh insight into our own situation. Therefore, we must either remove ourselves from the chaotic horror of existence (through suicide – a choice that Zapffe regards as both rational and in some senses therapeutic) or attempt to anaesthetise ourselves so that we are rarely forced to experience these moments of what Zapffe describes as 'cosmic panic'. Zapffe lists four techniques by which we seek to achieve this: isolation, anchoring, distraction and sublimation. Though we rely heavily on these techniques, Zapffe believes they offer a limited protective value.

In this paper, I suggest that in the light of current reproductive trends, the human species is indeed facing self-destruction, because we – especially women – have found better things to do than to reproduce. Birthrates are declining and will continue to do so if other things that we regard as valuable – the eradication of poverty, the global acceptance of gender equality – are achieved. Whether these *can* can be achieved, are questions that I cannot answer here. But I will show that *if we think they should be* this could bring Zapffe's pessimistic prophecy closer to fulfilment, albeit not in the way he imagined.

Zapffe himself regarded women as being less susceptible to 'cosmic panic' because they are "…in general less cognition-prone and hence more secure in their living than men". I will show that reproduction, in conjunction with the subservient status of women served to fulfil a powerful anchoring and distraction strategy for the avoidance of the kind of horror that Zapffe discusses. Once we achieve gender equality so that women are not impoverished, and are freed from the shackles of uncontrolled fertility, we may be better able to recognise *women's* accounts of their pessimism and despair. But this will come at the cost of a considerably increased risk to the survival of our species. Not only does it free up half of our species members to join in the collective despair, it threatens the status of reproduction itself as one of our most effective anchoring and distraction techniques. There are ethical questions, of course, as to whether in view of the correlation I am arguing between despair and the eradication of women's disadvantages, we *should* continue to press for economic and gender justice. This is a question I cannot attempt to answer in this paper, though I acknowledge its importance.

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[1] Zapffe PW. The Last Messiah. Philosophy Now. Issue 45. https://philosophynow.org/issues/45/The_Last_Messiah

[2] All direct quotes from Zapffe in this paper are taken from The Last Messiah. For simplicity I have not appended a reference to each quotation

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Bio(po)ethics: On the use of different art forms in teaching bioethics

Solbakk, Jan Helge
j.h.solbakk@medisin.uio.no

What should one aim at when teaching bioethics to students? Six standard answers often referred to in the literature are: to raise awareness; to foster reflection and self-reflection; to increase moral understanding; to promote dialogue and deliberation; to enhance moral sensitivity; and to develop moral skills. In this paper the aim is to demonstrate how the use of different art forms in teaching bioethics might generate additional forms of moral learning that deserve more attention than hitherto given. Four such forms will be demonstrated. In metaphorical terms the aim of each of these forms can be described thus: to generate some sort of *movement*; to produce some of sort of *purification* (*catharsis*); to foster *therapeutic doubt*; and finally, to reduce *moral blindness*.

Autonomy and Erosion of Trust in the Doctor-Patient Relationship

Soniewicka, Marta
marta.soniewicka@gmail.com

In my paper I will analyze a philosophical concept of autonomy as applied to the doctor-patient relationship. I will start with comparing different interpretations of the concept, namely the one based on Kantian philosophy, and the other rooted in the utilitarian philosophy of John Stuart Mill. I will elucidate why the idea of patients' autonomy institutionalized in the informed consent is not fully sufficient to meet the assumptions of the full-fledged philosophical conception. I will also address the problem of the tension between the principle of patients' autonomy and the idea of trust between a physician and a patient, claiming that one may make these values compatible within a broader philosophical scheme rooted in Aristotelian philosophy and the ethics of care. I will attempt to explain the problem of trust erosion in the doctor-patient relationship by invoking the "crowding out effect" (also known as the "over-justification effect" or the "corruption effect") which may be interpreted as the competition between incentives which results in the substitution of intrinsic (moral) motivation in an agent by extrinsic (economic, or legal) one which turns out to be counter-productive. This effect may be found in the healthcare context explaining why bureaucratization, commercialization and over-legalization of medical practice have adverse effect on the medical practice and the physician-patient relationship.

Review of End-of-life Guidelines – the Ethical Aspect

Špoljar, Diana
dianaspoljar@gmail.com

The principles of bioethics are widely known and woven into many guidelines and recommendations. They are long-established with the intention to protect the patient's health

and other values, and to help physicians make best clinical decisions which are in the patient's best interests. End-of-life is a very specific and distinct area in medicine and in ethics, as it deals with issues of outmost sensitivity. Patients, their families, and medical staff are all involved in the decision-making process which often includes a great deal of emotional energy, apart from the usual considerations for best clinical practice and patient's values.

Many institutions, national and transnational, governmental or non-governmental, have issued recommendations and guidelines regarding treatment of patients at the end-of-life. These guidelines focus on specific questions and help physicians make the most suitable decisions. They offer advice on a variety of issues, such as: communication with the patient and family, pain management and sedation, mechanical ventilation, withholding and withdrawing of treatment, intentional termination of life, etc.

This article explores the ethical arguments and concepts described and entailed in aforementioned guidelines which help in the decision-making process at the end of life. It focuses on identifying ethical issues, on exploring how they are dealt with on a theoretical and practical level, and on recognizing main arguments underlining each of the principles. Three particular areas of end-of-life are more specifically addressed: withholding / withdrawing of treatment, palliative care and palliative sedation, and intentional termination of life. Practical recommendations on clinical practice and protocols are analysed as well.

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Professional Ethics at Neonatal Intensive Care Units

Stanak, Michal; Hawlik, Katharina
Michal.Stanak@hta.lbg.ac.at

Introduction: At the backdrop of their particular socio-cultural, religious, and legal context, neonatal intensive care unit (NICU) professionals encounter many ethical challenges especially when it comes to interventions at the limit of viability (weeks 23+0 to 24+6 of gestation). We explored the challenges in the Austrian NICU context that operate at the backdrop of Kantian philosophy of deontology, Christian culture, legal requirement of prolonging life without caring about its quality, socio-economic inequalities, and current migration challenges.

Methods: A mixed methods approach was applied. First, a comprehensive systematic literature search was conducted to gather the available evidence. Secondly, interviews with the heads of the departments for neonatology of five perinatal care centres and a clinical ethicist were conducted to gather data specific to the Austrian neonatal context. Data from the systematic literature search as well as the interviews were analysed separately and subsequently integrated into a literature review.

Results: Challenges connected to uncertainty, best interest, and fairness were the main sources of moral dilemmas. The main causes of uncertainty were a) the imprecision of baseline and outcome data of extremely premature (EP) babies, b) the lack of empirical data on what it is to live through the experience of active or palliative treatment at NICU. Further ethical challenges come in when attempting to discern the fair course of action that is in the best interest of the EP baby as the goal of neonatal medicine is to minimize undertreatment as well as overtreatment and avoid gestational ageism.

Handling of an ethically challenging situation also differs between hospitals and between countries. Depending on whether clinical ethics is taken to be an integral part of medicine, ethics committees and ethics support play an important role in systems of countries such as the UK. In Austria, there is variation in the role that ethics play in different NICU centres. Recognition of the role of ethics requires a recognition that answering the obvious question (what shall we do?) does not always suffice. Acknowledging the tragic question (is any of the alternatives open to us free from serious moral wrongdoing) and recognizing the ethical dilemmas, where the lines between right and wrong are blurred, leads to actions taken towards establishing ethics frameworks to support decision-making. In NICUs, such structural support can help in allowing the team members to recognize the ethical dilemmas, avoid moral distress, and improve team cohesion and the quality of care provided. Only when the organizational structure allows ethical dilemmas to be recognized, adequate decisions can be made.

Conclusion: NICU professionals attempt to save each baby that has reasonable chances for meaningful survival and let go the one that does not in order to prevent unnecessary harm. In doing so, we concluded that the presence of moral dilemmas as well as the role for clinical ethics (and ethics committees) need to be recognized in order to avoid moral distress and improve team cohesion in Austrian NICUs.

Phenomenology & Ageing

Stanier, Jessica
jessica@stanier.co.uk

With an ageing population, and the growing issue of care for the elderly, it will become increasingly important to understand old age by disentangling notions of time. Geriatric diseases are neither intrinsic to, nor inevitable in, old age but are nonetheless linked. It is important, therefore, that we have account of ageing that clarifies this link and pays due attention to the temporal and bodily changes that old age can entail. Chronological time, biological time, phenomenological time (time-consciousness), and narrative time are crucially different gerontological concepts for understanding the life course.

In this paper, I argue that becoming aged entails a specific existential bodily experience in space as well as time. Taking my cue from disability studies, Garland-Thomson's 'misfit' theory is instrumental to my understanding the aged body as passing into an incremental material misfit with its surrounding environment. In this way, I seek to resist the dichotomy between social constructivism and bodily facticity. I also interrogate Waiss' reading of Merleau-Ponty to see whether parallels across phenomenologies of normativity (e.g. gender, race, disability) can be extended to the experience of ageing. I propose that changing spatial boundaries of the homeworld are ultimately what structures the experience of ageing through time.

Faith in Health Care

Stempsey, William E
Email: wstempsey@holycross.edu

This is a philosophical analysis of the theological virtue of faith in the context of health care. I first consider some ways that faith has been understood by philosophers and theologians, including Thomas Aquinas, Immanuel Kant, John Paul II, Henry Nelson Wieman and Jaroslav Pelikan. I then differentiate what I call "shallow faith" from "deep faith." Deep faith helps patients, health care providers, and researchers to appreciate that health care is not only about correcting biological dysfunctions of the body, but also about relieving the suffering of patients and helping them to come to terms with the reality of death. Shallow faith does not refer to degree of religious commitment, nor is it necessarily bad and always to be avoided. Faith may be shallow in three ways: (1) it may have an improper object, as when one's faith it placed entirely in medical science, ignoring deeper questions of the meaning of suffering and death.; (2) it may be completely disassociated from reason, ignoring the philosophical connection between faith and reason argued for by such disparate thinkers as Thomas Aquinas and Immanuel Kant.; (3) it may distort the physician-patient relationship, with an impoverished understanding of the moral nature of the relationship that is foundational for health care. According to Arthur Kleinman, human beings seek meaning in their illnesses on four levels: (1) the meaning of symptoms themselves; (2) the cultural meaning of the illness, which shapes a level of meaning for individuals; (3) the personal meaning of the illness; (4) the social meaning for patients, families and health care providers of all aspects of an illness and treatment. Humans are meaning-seeking by their nature and they suffer because of crises of meaning as much as they suffer from biological dysfunction. As Eric Cassell has eloquently argued, it is the whole person that suffers, and persons are complex; suffering can occur at any level of the person and the level at which suffering occurs is unpredictable. Cassell has also showed how meaning and transcendence can meliorate suffering. Deep faith can lead all involved to a fuller appreciation of the mysteries of suffering and death. It can help a patient to situate suffering and death in a larger transpersonal context and recognize more fully the nature of suffering and ways that transcendence can lead to some relief of suffering. In developing the notion of deep faith, I draw upon the William James's "will to believe," Joseph Pieper's work on the relationality of faith, and Gabriel Marcel's "creative fidelity." Deep faith brings several of the characteristics classically associated with faith to the context of heath care in order to enhance the relief of suffering through finding meaning. I conclude with some implications for patients, physicians and researchers.

Narrating pain. Chaos and the requirements of narration

Streeck, Nina
nina.streeck@uzh.ch

Dealing with chronic pain means dealing with disruptions: If a person realises that her pain will not vanish but stay this may be a life-changing experience. Not only may she have to adapt to changes, e.g. within her family life or her professional career, but also her daily routines turn into a challenge. Whenever pain kicks in it disrupts normal life what may be experienced as if chaos takes over. Narrating such chaos is not an easy task. As Arthur Frank put it, chaos even makes storytelling impossible wherefore chaos stories, as true "anti-narratives", can only be lived but not be told. Above that, the pain sufferer who wants to narrate her pain will have to talk about something invisible to others. As a consequence, it is difficult to hear and make sense of such narratives.

Within narrative ethics and narrative medicine, though, it is suggested that chaos could be negotiated through creating a coherent story and thereby reintegrating one's identity. Hence, those who succeed in leaving chaos behind in that vein are suggested to be able to lead a good life. However, it is questionable whether coherence can always be achieved. How are the difficulties in narrating chaos overcome when people with chronic pain tell the stories of their illness? How much chaos can a narration bear so that it still can be considered a story? And is narrative coherence a prerequisite for storytelling?

Questions like these will be addressed drawing on interviews with chronic pain patients as well as on examples from literature. It will be explored how chronically ill persons put their pain into words and how they deal with the challenge of making themselves understood. On this basis, it will be argued that the requirement of narrative coherence proves to be too demanding. Nevertheless, telling chaos stories neither results in incomprehensibility nor does it necessarily lead to a disintegrated life.

In the name of life: Death and the institutionalization of life in the modern state

Stronegger, Willibald J
willibald.stronegger@medunigraz.at

Background: During a lecture in 1989, Ivan Illich specifies the dangers that accompany the biologization of the legal person, as well as the reduction of the 'sentient human being' to '*a* life', with the following words: "Thinking in terms of '*a* life' and 'human life' vaguely connotes something of extreme importance and tends to abolish all limits that decency and common sense have so far imposed on the exercise of professional tutelage… '*A* life' is amenable to management, to improvement and to evaluation in terms of available resources in a way which is unthinkable when we speak of '*a* person'". The distinction between Illich's 'human life', being subject to optimization and enhancement on the one hand, and that of a person or legal personality unavailable to these procedures on the other hand, is in a similar way present in Michel Foucault's concept of biopower or biopolitics.

Objectives: Foucault repeatedly points out that the emergence of biopower is consequently accompanied by a 'régression du juridique' in favor of a 'jeu de la norme'. Its theoretical framework is not "the building of law, but the field of human sciences", based on a reductionist concept of nature. The main goal of a biopolitical society is securing and functionally establishing 'human life'. This being the central task of the biopolitical state, how can death and dying become acceptable and integrated institutionally, if old age and dying are so contrary to functional aims inherent to the system?

Results: In accordance with biopolitical rationality, only two ways of dealing with death are feasible: either death is a non-systemic event that remains excluded, or death is an entity embedded in the systemic rationality. In the first case, death appears as a 'failure', marking the ultimate limit of all institutionalizations of life with its aspirations of 'faire vivre'. Death is to be prevented with all available measures; life is to be prolonged and preserved for as long as possible. This approach leads to medical overtreatment and high expenditures at life's end.

In the second case, death is legitimized within biopower, its rationality however differing fundamentally from that of juridical societies. It refers to 'a power to make live and reject into death'. This asserted 'right' to 'reject into death' arises from a comparative assessment of life and is not founded by fundamental principles of law, as the public law itself has become a biopolitical 'social technology'.

Discussion/Conclusions: In the rationality of biopower, death is only acceptable as a consequence of human action. Either as a final failure of all human actions and life-sustaining efforts, or as a complete negation of failure, as a 'faire mourir' in the name of self-determination and life - or of love, as contemporary literary and cinematic adaptations suggest. The question remains whether, in today's expression of biopower as liberal governmentality with its own manners of collectively controlling individual decision-making, a professional service for 'rejecting into death' based on the individual demand could become a reality.

Why future doctors should read literature?

Sutrop, Margit
margit.sutrop@ut.ee

The aim of medicine is to maintain and restore the health of the patients. Health is according to the WHO the state of complete physical, mental and social well-being and not simply the absence of disease or infirmity. Unfortunately, in many countries the future doctors are still taught to focus solely on the physical side of the patients' well-being forgetting that the patients mind and body are connected and the mental and social problems influence their well-being. Deciding what is in the best interest of the patient the doctor should take interest also in what the patient is scared of, what she values and desires.

My experience as a member of the university clinical ethics committee shows that most of the conflicts between doctors and patients have their origin in communication problems. The doctors do what they think is the right thing to do on the basis of scientific evidence without taking into account that the patient is a human being in a specific life-situation. My diagnosis of such conflicts is that some doctors simply lack imagination, empathy and sometimes also the necessary social skills. All these skills can and should be taught as a part of the medical curriculum.

In my paper I am going to argue that the best way to develop one's capacity for imagination and empathy is through narratives which can also be fruitfully used in teaching medical ethics. Reading fiction helps the future doctors to understand better their patients and situations in which medical treatment takes place. I am going to show that this effect is achieved because fictional texts evoke two kinds of acts of imagination. First they enable the reader, through his or her imagination, to place themselves in other people`s shoes and to see the world from perspectives different from their own. This kind of imagination is a source of empathetic sharing of emotions. Second, they provoke the reader to create meanings, causing him or her to reflect both on what is happening in the work of literature and in their own experience, which fosters the development of the reader's understanding and moral character. When constructing the meaning of the literary text, the reader ponders the complexity of the world and becomes conscious of her own values, sometimes even proceeding to critically reassess them.

The legal aspects of providing medical services to adolescents

Szymańska vel Szymanek, Paulina
paulinaszymanska31@interia.eu

The aim of the presentation is to indicate the most significant legal problems that occur in case of providing medical services to adolescents. Although the above-mentioned issues have not only a legal, but also ethical and psychological aspects, they will be described in the scope of international and Polish legal regulations.

First of all, the question why the teenagers are a very special group of patients needs to be answered. The adolescences are still under parental authority, nevertheless their need for autonomy and independence is much greater than those of younger children. Moreover, they are usually dissatisfied with their appearance; face the lack of self-esteem and the peer pressure (it is the great problem especially among the teenage girls). There are also various aspects related to sexuality, which young people do not want to share with their parents.

Secondly, the legal standards shall be presented. The general rule is that the medical intervention may only be carried out with the authorization of the minor's legal representative. In the most cases parents' decisions are in accordance with the welfare of the child, however there are situations where the child's autonomy may be jeopardized.

This may happen especially in the area of: gynecological care (the most common situation is the question of providing contraception without parental knowledge and consent, which is not allowed under the Polish law) and the aesthetic interventions. In the first instance, there may be a risk of breaching the right to privacy of adolescence. The second example, concerning especially aesthetic surgery, raises the question about the limits of the autonomy of teenagers and their right to decide about his or her own body.

The issues described above are all the more important due to the fact that they are not regulated specifically under the Polish law. The last part of the speech will focus on the possible ways of solving the above –mentioned problems. It is particularly worth referring to the provisions of the other European countries as well as to the international medical and ethical standards.

Are bioethicists examiners or producers of the ethical, legal, and social implications?

Takala, Tuija
tuija.takala@helsinki.fi

Recent studies have shown how people tend to trust articles with colorful brain-imaging pictures more than articles without such photos. "A picture tells more than a thousand words." What most people fail to understand, however, is that brain imaging pictures are not photographs. They do not reproduce a visual image by capturing light on a sensitive surface. The images produced are visualizations of correlations of neuronal activity interpreted through complex theoretical assumptions based on computerized algorithms created from databases of brain activity patterns. At its simplest, a bioethicist's task could be to try to correct, or at least, point out misconceptions like this before they are allowed to lead to unwarranted ethical, legal and social implications. Of course, others, including neuroscientists themselves could be doing this, but as philosophers, one of the aspects that bioethicists should be assessing is the truth value of the premises on which decisions are based.

More profoundly, philosophical analysis can help bring to the forefront the theoretical assumptions that lay behind claims that advances in neurosciences should have these or those ethical, legal or social implications. Depending on one's views on the relationship between mind and matter, free will and determinism, and on one's definitions of, say, identity and personhood, the advances in neurosciences will come to have vastly different implications. Add to these all the different theories of ethics, of social justice and law and it becomes obvious how much preliminary analysis is needed before we can discuss what ethical, legal and social implications a particular advancement should entail.

In my talk, as an example, I will look at the recent developments in functional magnetic resonance imaging and their suggested ethical, legal and social ramifications. I will show how, at all levels philosophical bioethics can help to broaden our understanding of the metaethical, theoretical and normative matters that need to be settled before jumping into the more practical recommendations. I will argue that philosophical bioethicists should, first and foremost, study the assumptions behind the suggested ethical, legal and social implications and only secondarily, and very cautiously, if at all, produce them.

The Concept of 'Recovery' in Social Psychiatry

Tengland, Per-Anders
per-anders.tengland@mau.se

'Recovery' is a term used in many contexts, and especially within medicine, care, and psychiatry. People can recover from a number of bad states, e.g., heartache, hunger, poverty, and indebtedness. However, given the context of this article, social psychiatry, the term appears to be about 'getting better', or even 'being healed' from a disease, disorder, illness, or similar condition. Even so, in the medical and psychiatric literature the term is used in a number of different ways, and a variety of end goals for recovery are suggested, some of which convey very different approaches to, or methods for, treating (helping, supporting, facilitating) individuals, users, clients, or patients, in order for them to recover.

That the term comes with many meanings becomes even more clear when one approaches the field of social psychiatry, where the 'recovery movement' in psychiatry makes both a theoretical and ethical/political point in viewing recovery as a very special, and 'valuable', process or phenomenon. The aim of this paper, then, is to formulate a definition of the concept that might be particularly useful in the context of social psychiatry.

First, the basic concept 'recovery' will be defined, abstractly, and second, it will be decided what, exactly, is the quality (or qualities) that the individual should regain. Several ideas about what the valued dimension should consist of will be discussed, e.g., symptom reduction, mental functioning, health, subjective well-being, happiness, quality of life, empowerment, and a meaningful life.

Research on ethical issues of assisted death and patient care. From the perspective of buddhist vinaya

Tu, Chun-Han
johntu531@gmail.com

The controversy over the ‘right to die,’ and the role of doctors in facilitating that right, has been a central concern of medical ethics since the Netherlands and Belgium legalized euthanasia and physician-assisted suicide in 2002. Meanwhile, the development of palliative medicine has been attracting increasing concern.

Buddhist Vinayas (commandments), orally passed down from the Buddha to his disciples, are not only the regulatory framework for the monastic community but also the ethical guide for lay practitioners of Buddhism. With respect to the issue of assisted death, the first precept of the vinayas, non-injury, condemns the killing of animate beings. In providing the instruments, such as poison or knives or praising death, the monks or nuns break the precept of non-injury. Some assert that according to the vinaya texts, Buddhism is in contrast with the modern practices of assisted death. On the other hand, according to the ethical guidelines of patient care in the vinayas, monks or nuns afflicted with illness deserve proper care of physical treatment and spiritual care.

This paper aims to clarify the Buddhist attitude toward assisted death and investigate how the Buddhist vinayas reflect ethical principles and regulations applicable to the modern hospice care by means of literature analysis, philosophical argument and case study. As for the issue of assisted death, this paper will draw on the case and the content of the first precept, non-injury, which condemns the killing of animate beings in vinaya texts, to demonstrate how the Buddhist vinayas forbid practitioners to kill, and the reason why the texts put some acts of assisted death and even praising death on a par with violation of the precept of non-injury. With respect to the issue of terminal care, the paper will discuss the case of patient care in the vinaya texts to indicate what ethical components of the vinaya texts can be cited as a basis for the spiritual aspects of modern palliative care.

Putting human experience at the centre of healthcare

Tyreman, Stephen
S.Tyreman@uco.ac.uk

There is an implicit assumption in Western medicine that human health and malady is fundamentally a physical, biological problem (with psychological and social modifiers) and that human being is best understood from ‘basic building blocks’ found at a genetic, molecular level, i.e., from mechanisms to organism. The arts, if they are important at all, merely dress human beings in culturally significant attire. My claim is that this puts the mechanistic cart before the organic horse.

Drawing on A.N.Whitehead’s ‘Organic Philosophy’, together with German holistic biologists and philosophers of the mid 20th Century, I will argue that human being is grounded in experience, where ‘experience’ is: engagement with the environment through all domains; perception of the environment and the nature of the engagement; the meaning given to it; plus the organism’s response. Organisms are not only necessarily whole and indivisible in their viable living state, they are intimately connected to, dependent for their existence on, and constantly adapting to their environment. Central to this is the person’s awareness of their environment—what von Uexküll termed the Umwelt—the meaning given to it and the organism’s response, which will be physical, cognitive, affective and social.

Perception on this account is not merely a cognitive, but a whole organism phenomenon that entails a complex set of ‘environmentally aware’ components, including genes, each of which effectuates an adaptive response and an on-going permanent relationship with the experience that gave rise to it. A person is built up, not from a finite set of genetic building blocks, but from an infinite array of experiences. This accounts for the unique individuality of human beings.

The arts have the ability to challenge, extend and clarify an individual's experience of their environment and hence their holistic development and sense of health and being. The arts are therefore fundamental to human being and not mere dressing.

Understanding vulnerability in health care. The case of addiction

Uusitalo, Susanne
susuus@utu.fi

All human beings are vulnerable *qua* human beings. However, the vulnerability of addicted individuals is also generally agreed upon. It seems to be something else, something particular, pertaining only to addiction. The claim may be based on various views, e.g., NIDA states, "[b]rain sciences generate evidence of the vulnerability of addicted individuals referring to pathologies of the brain, typically induced by drug use", whilst the Global Commission on Drug Policy stresses that the vulnerability caused by drug policies is often more harmful than the pathologies of the brain. Both of these views suggest that individual's autonomous agency is undermined. Pathological vulnerability suggests that the use of drugs is compulsive. Social policies amount to external controlling influences for the agent. However, I suggest here that vulnerability is not automatically potentially harmful and unjust, but it can also be a resource (not only in terms of vulnerability as a universal human condition, but also in other respects).
This has implications for the normativity of vulnerability in addiction in health care. Typically, this vulnerability requires measures; if possible, it should be prevented and mitigated, or if not, action should be taken either by protecting the vulnerable or making sure that they will not be subjected to harm. If vulnerability in addiction does not necessarily amount to an indicator of normative action, does it lose its plausibility in health care? I will suggest that it does not, as it serves a useful tool in research and treatment: not only does it indicate points of potential interventions but also enables individuals to employ their vulnerabilities in a productive manner. This requires that it is understood what vulnerability actually means in this context; it is far from reducible to impairments of competence due to heavy drug use. Consequently, it requires a more nuanced reading.

Codifying Humanism: A Transition in Medical Education

VanDyke, Amy M
Amy.VanDyke@mchs.com

The modern outcomes based movement in medical education began several decades ago. Since then several important philosophical changes have occurred. Outcomes-Based medical education (OMBE) commonly referred to as competency-based education has attempted to improve the preparation of physicians. Educational changes have occurred, in part, in response to the consequences of burnout experienced by trainees; including such things as poor academic performance, depression, increased suicidality, and general poor performance. This is balanced against co-existing changes in modern healthcare such as the need to reduce patient harm from medical error, improve patient experiences and thus satisfaction metrics in the highly competitive health care marketplace. Moreover, implementation of shared decision-making models which are dependent on the co-production of health care outcomes with patients are among the drivers in the transition of medical education effort. It is believed that here has been a discernible gap in training physicians on patient interactions and patient engagement and that previous medical education models have insufficiently acknowledged the human experience of physicians in training.

The Accreditation Council for Graduate Medical Education (ACGME) has recently instituted major changes to the common program requirements for residency training. These changes went into effect in July 2017. ACGME along with Liaison Committee on Medical Education (LCME) now, essentially require that residency programs teach physicians in residency programs how to connect to the patient. This connection to the patient is that liminal space which engages the science of medicine with the art of caring for patients in addition to the recognition of the humanity of both parties engaged in the healing relationship.

This presentation will briefly examine the philosophical underpinnings of medical education from an historical Flexnerian paradigm to current programmatic philosophies in medical education. These transitions, whose philosophy is leading normative ethical changes in what constitutes good medical education/practice, include incorporation of physician trainee needs along with the needs of the patient. The overarching goal is improving outcomes on both ends of this delicate and necessary relationship. Changes being incorporated into current educational efforts may challenge the longstanding and comfortable dichotomy which has been established between physician and patient. This dichotomy has offered some level of protection for physicians who could focus on an interesting and complicated case instead of the human patient experiencing the distressing illness.

This presentation will then focus on specific changes being seen in graduate medical education residency programs which now must incorporate education on how to apologize for medical error, efforts to focus on resident well-being as a core part of the curricula, yearly incorporation of skills to identify and address depression/burnout, and managing difficult doctor/patent relationships with evaluation tools to examine and improve communication skills and competencies. Discussion of the above paradigm shifts in medical education will be framed around programs based in the United States of America.

Homesickness or Nostalgia in the Fictional Works of the Brontë Sisters

Vembar, Harini
harini.vembar@umu.se

Towards the end of the 17th century, a young ambitious student called Johannes Hofer coined a neologism called nostalgia from two Greek words, *nostos* (return) and *algos* (pain or longing) or what is now colloquially termed homesickness. From the end of the 17th century and up until the end of the 19th century, nostalgia continued to be perceived as a physiological and mental ailment and had a wide spectrum of cures ranging from a return to the homeland to live burials. The theme of nostalgia or homesickness persists in the works of innumerable writers, especially evident in the fictional landscapes of the Brontë sisters. Emily Bronte's famous protagonist, Catherine Earnshaw of the novel *Wuthering Heights*, wastes away because of her depressive traits, and eventually dies as her homesickness is extremely severe. In Charlotte Brontë's *Villette,* we see that Lucy Snowe is nostalgic for her old home in England at several occasions. The Brontë's range of fiction often feature the dislocated heroine who longed to go home, whether it was a governess figure like Lucy Snowe or a high society lady like Catherine Earnshaw.

Examining fictional spaces that explore the topic of homesickness will help us understand this subject in a more empathetic manner. In this paper, I explore the various emotions caused by nostalgia and homesickness in contemporary and Victorian literature to see how writers' express homesickness in literature.

That literature captures the human condition of loss, pain and suffering and thereby, enables the reader to understand the protagonist's ailments is not a new theory in medical humanities. However, the subject of homesickness or nostalgia has been neglected to a large extent. In this

paper, I propose that exploring this subject through the lens of writers from various eras will not only recover the historical concept of the word, but it will also enable us to understand how individuals from various periods adapted themselves to homesickness and thereby, contribute to the study of nostalgia and homesickness. It is highly imperative to understand the much-neglected subject of homesickness or nostalgia today as geographical relocation affect several communities and factions of the society. The paper discusses the following questions with relation to the chosen texts:
1) How do literary writers convey nostalgia or homesickness to the readers? How does the lens of nostalgia studies as a mental ailment add to the text?
2) How does nostalgia or homesickness manifest more tangible symptoms such as anxiety or depression?

Ground truth in the human domain: Will artificial intelligence yield purely objective definitions of health and disease?

Vogt, Henrik; Hofmann, Bjørn; Getz, Linn
vogt.henrik@gmail.com

Medicine is ever confronted with questions of validity and verification. For example, how do we know what is health and disease? In particular, this is a challenge as disease and health cannot be separated from the whole person and his/her environment and general functioning. George Engel, the pioneer of the biopsychosocial model, stated that the challenge of medicine is to be "*scientific in the human domain*".
Against this backdrop, we are currently witnessing the emergence of a novel medicine, variously called precision medicine, high definition medicine, digital medicine, systems medicine and P4 medicine (predictive, preventive, personalized and participatory). This vision is in large part based on novel opportunities for gathering and analysing big data using artificial intelligence (machine learning) and mathematical modelling. One promise found in this new vision and projects like Google´s "Project Baseline" and The Institute for Systems Biology´s "100K Wellness Project", is that human life is to be mapped in a comprehensive manner through longitudinal monitoring, yielding purely scientific and quantitative definitions of health and disease. These new "metrics" for health and disease will, it is promised, eliminate the purported vagueness, ambiguity, and incompleteness—that is, uncertainty and normativity—of previous definitions. However, it is also uncertain precisely how this definitional process is to be performed.
In artificial intelligence one often uses the term "*ground truth*" to denote data that reflect the "real world" against which a model or algorithm can be trained and compared. Drawing on René Dubos and Georges Canguilhem, it is here argued that, when defining health and disease, artificial intelligence will have to be calibrated against a ground truth that is dependent on the normativity of human nature. The argument also draws on a paper that examines in detail a concrete and relevant piece of evidence that sheds light on the question of how health and disease is to be defined in big data medicine: A patent for a "Multiparameter analysis for predictive medicine" co-authored by Leroy Hood, one of the new medicine´s prime advocates. This patent describes a systems medicine method for assessing health and disease. At the heart of the definitional process we find judgements made be "*people skilled in the art*" as to what disease and ideal health is. Although big data and systems medicine is promoted as heralding an era of transformative scientific objectivity, the patent provides evidence for the theory that algorithms and models based on artificial intelligence will also rest on normative judgements. Behind the quantitative façade, we thus locate a qualitative core, and *the art of medicine*.

Palliative care exceptionalism: Shaping identity and reconfiguration of modern medicine

Vollmann, Jochen
jochen.vollmann@rub.de

Palliative care is an innovative and growing field focussing on life-threatening illness and on the relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. In this holistic approach palliative care differs from science based modern medicine and shows similarities to other holistic approaches to the patient as a subject as well as to pre-modern medicine.
Palliative care exceptionalism is analysed in a broader perspective on end of life care and modern medicine. I will show how palliative care may change the identity of modern medicine and also its' limitations for a major reconfiguration of modern medicine and future health care.

The epistemic status of narrative and improving patient care

Walker, Mary Jean
mary.walker@monash.edu

Narrative medicine – medicine practiced with narrative competence – has been proposed as a way to make the practice of medicine more humane, as well as to improve its effectiveness (e.g., Charon 2006). In this paper I focus on a sense in which the latter claim, regarding effectiveness, could be true. The paper will examine discussions of narrative in the philosophy of history and literature, and argue that the form has a distinctive epistemic use, in helping to form and communicate judgements of significance, relevance, or salience. Narratives help us to perceive that particular events or features of sets of events are important, in relation to particular contexts and purposes. This account of the epistemic status of narrative also helps to clarify when and why narratives might mislead or distort our understanding of a condition. I then apply the account to the case of medical practice and examine examples, to clarify the role of narrative practice in improving medical care.

Muslim Medical Students on the Meaning of Disease

Weber, Alan S
alw2010@qatar-med.cornell.edu

Research Object: To understand Muslim medical students' beliefs on the origin of disease.
Background: Both patients' and medical practitioner's beliefs about how illness arises and how sickness shapes world views, daily living, and cultural and religious patterns can impact therapy choice, help seeking behaviors, the patient perspective on disease, and patient-provider relations, etc.
Methods: The research examined 64 Muslim medical student essays responding to the question "what is the origin of disease and why do people get sick?" written in a 1-semester medical humanities course in the State of Qatar at the Weill Cornell Medical College in Qatar from 2006-2017. Themes were coded in NVivo 11.0 qualitative software using standard ethnographic techniques.
Results and Discussion: >80% of WCM-Q students are Arabian Gulf Arabs professing Sunni Salafist or Wahabist Islam, thus the responses were frequently framed with reference to religion and Allah. Several repeated and clear themes arose: *1. disease as test:* "one of God's purposes to create disease is to test the human race whether they can still be good even if they were in

unfavorable situations or not." *2. disease equalizes humanity*: "even the biggest and most powerful of men can succumb to the effects of viruses or diseases ….this just shows how, even as advanced as we are now, we are all equal human beings created by one being." 3. *health as gift from God:* "diseases are a reminder for us of the great health that God has granted us, and that we should not forget to thank him all the time for this remarkable gift" *4. punishment for immoral behavior:* when an addict "gets addicted to drugs, the consumer gets more diseases mentally and physically…this confirms that breaking God's rules results in imbalance, which is disease."

Conclusion: Beliefs concerning disease origin have shifted over time and vary considerably in different cultures, from magical, religious, and folk traditions to a series of bioscientific paradigms including internal balance (Hippocratic-Galenic Humoralism), the Germ Theory, Environment, and Genetics. Practitioners and physicians-in-training should remain self-reflective about their own medical philosophy and develop empathy towards diverse views on the origin of disease in order to deliver patient-centered culturally sensitive care.

Mobile technologies against Gender Based Violence? The ethics of including women's voices, relations and structural background conditions

Wild, Verina; Eisenhut, Katharina; Mitra Ganguli, Agomoni
v.wild@lrz.uni-muenchen.de

Gender Based Violence, GBV, is a multidimensional phenomenon with consequences of physical and mental health requiring prevention, support and redress at different levels and from different angles. One such mode of relatively new interventions lies in the use of mobile technologies. Various apps are currently being developed and deployed, aimed at preventing GBV, or to provide immediate support in times of acute crises and distress. However, the ethics of using mobile technologies against GBV remains underscrutinised, and we aim to begin a systematic ethical discussion with this paper.

First, we discuss a selection of mobile technologies, specifically apps, relevant to the discussion. On the basis of a review of the (currently) small body of scholarship, but also on the basis of advertisements, media or other reports, we identify emerging trends: How are the apps embedded in other strategies addressing GBV? What values and norms motivate the development of such apps? What narratives are used to promote the apps? How do the development and use of such apps impact on existing norms and values?

As a second step, we discuss our normative framing of apps in the area of health and prevention. This framing is informed by our previous research in the area of medical and public health ethics. It includes the importance of understanding the complexity of phenomena such as GBV, and the difficulty to do justice to this complexity in prevention and support approaches. It includes the necessity to listen to women's voices and stories and to fully acknowledge their testimonies (epistemic injustice, Fricker 2007); the necessity to understand and acknowledge relational aspects, power imbalances and oppressive patterns (relational equality, Anderson 1999); the importance of unpacking and addressing structural background conditions (structural injustice, Young 2011); and a deep and nuanced engagement with the concept of vulnerability (Mackenzie et al. 2000; Straehle 2016). The example of apps against GBV is well suited to illustrating why and how these dimensions should inform the discussion and evaluation of mobile technologies in the area of health and prevention.

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Presumed Dissent? To what kinds of organs and tissues ought presumed consent apply?

Williams, Nicola Jane
n.williams2@lancaster.ac.uk

Within the philosophical literature on organ donation it is often claimed that a legitimate alternative in countries where the explicit consent of would-be organ donors (and/or their families, post-mortem) is required would be the implementation of a policy of 'presumed consent', also known as 'opt out' or 'deemed authorisation.' Under such systems individuals are presumed to be willing to donate certain or all of their organs after death unless they have explicitly refused to do so.

Opt out policies for organ donation may differ in a number of respects, such as, for example, in the role and importance they assign to the families of potential organ donors and in various exceptions and safeguards built into the policy. Such exceptions normally specify groups of persons for whom explicit consent for organ donation should still apply such as children, adults lacking capacity, foreign visitors, and cultural and/or religious groups known to be opposed to organ donation. There is, however, a different kind of possible exemption that has been implemented in opt out systems and which applies, not to particular groups of people, but to particular organs and tissues. A notable example of this is that of the Welsh opt out system where the majority of composite tissues have been excluded, and require explicit consent for donation.

This paper explores this second type of exception, asking whether systems for post-mortem organ donation *ought* to limit the kinds of organs and tissues for which consent is deemed. This is done, in main, through exploring the extent to which two different policy proposals, one which presumes consent to donate all organs and tissues, and one which presumes consent to donate only certain organs and tissues, will serve to better fulfil the primary goals motivating shifts in organ donation policy:

1. Increasing the supply of organs and tissues for transplant and/or saving lives.
2. Better reflecting individual preferences regarding post-mortem organ and tissue donation.

Ambiguity in Medicine

Keicher, Franca; Wu, Ting Yu
tw2617@columbia.edu

The philosophy of phenomenology distinguishes itself from a longstanding tradition of a separation of the mind and body in Western thought. Central to phenomenology is the experience of 'being in the world,' a notion that the individual's intentionality is always directed *at* the world, and his or her consciousness always exists readily *for the* world, as the world for it. What follows the notion of intentionality in consciousness is the idea that the individual's subjective experience takes precedence over an objective absolute truth.

Simone de Beauvoir, in her work *The Ethics of Ambiguity* written in 1948, comments on an aspect of phenomenology that draws attention to the ambiguity inherent in an individual's experience seeking meaning from the world through an intentional consciousness that ironically reveals the self as "nothing more than an individual in the collectivity in which he or she depends" (Beauvoir 6). Consciousness is thereby an ambiguous activity, because while it repeatedly seeks to discover meaning, it escapes closure precisely by its involvement to disclose an ultimate sense of self. Yet the individual experience of “being in the word” does not end with the story of the intentionality of our consciousness. Rather, as Simone de Beauvoir points out in *The Ethics of Ambiguity,* our consciousness is an inherently ambiguous activity, because it exists neither in pure inwardness nor in pure exteriority alone, but in both. In his or her “being in the world,” the individual can never be detached from the interpersonal relationships by which his or her individuality is made known.

Understanding ambiguity of individual consciousness has important implications for the practice of modern day medicine in the world today. The idea of an ultimate truth has encapsulated Western society for centuries and has since spurred the innovations of science, technology, and humanistic investigations of the human condition in the form of art and literature. Yet in Western medicine today, the notion of a universal truth stands in stark contrast to the idea of ambiguity. The realm of Narrative Medicine aims to embrace and examine the concept of ambiguity more thoroughly in the practice of medicine. For the purpose of this paper, we will examine the roots of Western traditions of individualistic, absolutist thinking by analyzing Leo Tolstoy's novel *The Death of Ivan Ilyich,* a text that has come to canonize the experience of death and dying in Western culture. Since Western culture has heavily shaped the way health care is being practiced and approached by nations around the world, our goals in this paper are to elucidate the roots of Western philosophy in the making of our experiences human illness and mortality. In particular, to better understand how a *lack* of ambiguity in the patient-doctor relationship may result in isolation, mistrust, and dissatisfaction with medicine. By introducing the concept of ambiguity through the lens of philosophy, literature, and narrative medicine, we would like to revisit the issues salient in modern day healthcare and address how understanding ambiguity as a new framework in medicine allows both healthcare professionals and patients alike to better approach the experiences of the human condition.

Max Weber's Legal-Rational Authority as a Framework for Understanding the Physician-Patient Relationship

Xu, Jonathan
x.jonathan@columbia.edu

Educator Joanna Shapiro writes in “Feeling Physician” that the informal medical school curriculum can convey that emotional detachment is the appropriate professional posture. Like the military, medicine is hierarchical with physicians at the top of the chain of command. The authority of physicians, Max Weber would say, is legitimized by a legal-rational framework. Physicians appeal to an impersonal rank system as well as clinical competencies that can easily reduce patients to a “bag of symptoms.” In this way, patients require intellectual sorting involving pulling words from the air and putting them into mental bins. Physicians who work at the interface of an institution and the public find that the legal-rational framework they operate under is insufficient for successful engagement with the patient. Adherence to the impersonality of legal-rational authority prevents the physician from a recognition of the selfhood of both themselves and the patient which keeps them from truly being present to the self and the other. Physicians, I argue, must recognize both their selfhood and the patient’s selfhood so that their patients can receive fair treatment as sick and suffering individuals. We use Hegel’s theory of reciprocal recognition to illustrate/understand this. This calls into question the practice of prescriptive competencies of bedside manner and even cultural competencies of medicine originally derived from recognizing the patient's selfhood, in favor of ways for physicians to truly recognize the selfhood of the patient.

Mapping ethical challenges in internal medicine. Implications to teaching ethics in the clinical field

Yakov, Gila
gilayak@gmail.com

Ethical challenges and controversies are common in the daily activities in medical departments and clinics. Students that will graduate from medical school will face such ethical dilemmas, thus providing them with the best tools to handle such challenges is essential. The Main Research Questions was what are the most common ethical issues physicians are facing in an internal medicine department? What are the most common approaches in handling such challenges, and could those strategies be utilized as educational tools for medical students?
The aims were to Map common ethical challenges and dilemmas ,explore ways of dealing with these in the internal medicine department in order to build appropriate and relevant teaching program for medical students. Twenty-three physicians were interviewed and the conversations were analyzed for repeated theme.
The most common ethical challenge identified through the research relates to the inherent ethical complexities imbedded into the relationship between medical stuff and the patient's family, such as family members exert pressure to obtain information about the patient's condition, or to prevent information from the patient, and family members seek to provide or withdraw treatment from the patient.
The findings indicate that the rights for confidentiality and autonomy of the patient are threatened by family need for information and requests to conceal troubling information. Requests to withdraw treatments and request for additional treatments (even if futile) thus interfering with physician's obligation for the patient's beneficence.
These findings emphasize the importance of physicians' ethical reasoning in the process of solving ethical dilemmas and conflicts in their interactions with family members of their patients. Moreover, Effective communication is the basis for ethical effective conduct that will benefit both the patient and his family members. Preparing students for such interactions by developing their communication skills based on real-life examples have the potential to reduce the misunderstandings, stress and anger during their future interactions.

Limits of consent for research and teaching on the dead

Zawiła-Niedźwiecki, Jakub
j.zawila-niedzwiecki@uw.edu.pl

Cadavers and cadaveric specimens are routinely used in both scientific research and biomedical education. In the not-so-distant past the practice was associated with barbaric practices. Grave robbing, illicit or extra-legal cadaver trade and other such methods were – and maybe even still are - used to obtain bodily material for education and research. Modern regulatory regimes and ethical standards have certain provisions for obtaining of such invaluable resource for biomedical purposes. In many cases these provisions are based on consent of either the deceased person or said person's living relatives. As in other areas of bioethics and biolaw special consideration is given to consent which is oftentimes justified as protection of autonomy. It isn't however self-obvious if that is the case and if the extent of permission given by decision-maker is the only constraint on such practices. Also in some cases consent may not be required with various justification.
In this talk I will discuss the internal and external constraints on consent given for biomedical practices using cadaveric material. Firstly, I would like to give a provisional classification of such practices and their normative features. Secondly, I would like to show how those normative features relate to regular consent practices as present in biomedical ethics. And finally, I would like to show how those analogies provide us with guidance as to the limits, binding force, and requirement for consent of various decision-makers involved in the process.

The guiding theme and question will be what values are actually basis for the demand for mechanisms of consent.

Fundamental rights, indigenous populations, their members and patents. Does patent law help to respect rights to genetic resources and traditional knowledge?

Zimny, Tomasz
tzimny@gmail.com

I analyse the efficacy of current European patent law solutions for the protection of rights of indigenous populations and their members, relating to traditional knowledge and genetic resources. Current progress in of medicine is sometimes a result of bioprospecting (search for genetic resources in nature) and use of traditional knowledge. Oftentimes the two are linked. Prospectors use traditional knowledge in order to identify organisms of potential use. Bioprospecting activities led to some clashes in the past, where prospecting companies were accused of biopiracy, i. e. bioprospecting without adherence to legal or ethical requirements[1]. Here, not only economic interests of groups but also rights of individuals (e. g. their right to health) are at stake.

Currently the rights of indigenous populations to their heritage and genetic resources are protected by the Convention on Biological Diversity (CBD), whose art. 15 states i. a. that parties to the CBD should take measures to ensure fair and equitable benefit sharing. An additional protocol to the CBD (Nagoya Protocol) states that Parties shall take measures (…) ensuring that traditional knowledge associated with genetic resources held by indigenous and local communities is accessed with prior and informed consent or approval and involvement of these indigenous and local communities. (art. 7).

In the EU the compliance with the above is ensured through regulation 511/2014/EU and domestic laws. The recital 27 to the 98/44/EU *Directive on the Protection of Biotechnological Inventions* states that if an invention is based on biological material of plant or animal origin or if it uses such material, the patent application should, (…) include information on the geographical origin of such material, if known. This is without prejudice to the processing of patent applications or the validity of rights arising from granted patents.

This does not provide adequate protection of the indigenous populations' or their members' interests. The provision does not allow to refuse a patent for material obtained through biopiracy. Attempts to introduce such measures were made (e. g. in Belgium) but fell through. An analysis of provisions and doctrine shows that it's unlikely that patent to such an invention could be denied basing on the morality and ordre public exception to patentability. In effect the perpetrator merely faces a fine (e. g. in Poland up to ~12 000 €) in case of biopiracy, which may be disproportionate to the benefits stemming from patenting and commercialisation of such invention. An amendment of patent law that would allow to stall the granting of a patent or effectively deny it in case of inventions developed through biopiracy, could be a more efficient measure to encourage ethical use of genetic resources, traditional knowledge and equitable benefit sharing with indigenous populations and their individual members (with respect to their right to life and health), when it comes to medical products. Existence of such measures could be an additional motivator to striking benefit-sharing deals with indigenous populations.

[1]e. g. Hoodia gordonii, Ayahuasca or Peruvian Maca cases.

To Care is Human: Care for the Caregiver in Israeli hospitals

Zuckerman, Shlomit; Ashkenazi, Limor Cohen
shlomit.zuckerman@gmail.com

Background: Since its onset modern western medicine have focused on the patient. Patient centered care, in medical ethics and law, emphasizes the importance of the physical and mental wellbeing of the patient, encourages positive communication with her, advocate for transparency and building trust relationships with her. Only rarely, in the clinical setting, do we put the caregivers' well-being on the spot. It has only been in the past decade and a half that physicians' and nurses' day-to-day burnout on the one hand and the stress and anxiety they handle, which may in some cases lead to as much as a post-traumatic stress disorder, following a medical error has been explored in the patient safety and medical psycho-social literature, both theoretically and empirically.

This paper focuses on support of the caregiver as a second victim to medical error. The synonym "second victim" has been coined in 2000 by Albert Wu and the phenomenon, which has been studies since then, was found to be extremely common (50-70% of caregivers will face it thorough their professional life, more so in disciplines such as emergency medicine, maternity care and surgery, and the scope of its negative effects is concerning. Those include short-term effects (lack of sleep, anxiety) and long-term effects (shame, guilt, self-doubt, anger). According to the literature, the process of dealing with medical error up to recovery of the trauma involves six stages: chaos and accident response, intrusive reflections, restoring personal integrity, enduring the inquisition, obtaining emotional first aid and moving on. Various tools have been developed, mostly by U.S. physicians and nurses, to provide support to caregivers who experience second victim symptoms.

The aim of this paper is twofold. First, it reflects hospital team members' own experiences as second victims of medical error (or severe adverse event) and their perception of existing institutional, or lack thereof, as it has been described to the author in her role as a medical risk manager. Secondly, it sheds light on existing and planned support mechanisms provided by the institution to second victims in Israeli hospitals. Creation and implementation of such support mechanisms is particularly relevant in Israel, as it became mandatory by the Joint Commission International accreditation system and the Israeli Ministry of Health for patient quality and safety approval. The challenges of building a robust and practical support system for second victims of medical error in Israel health care and legal systems, given its unique characteristics, are discussed and several recommendations are made, as milestones for creating such practical and effective support mechanisms.

PARTICIPANTS

Surname	Name	Email
Ahlzen	Rolf	Rolf.Ahlzen@kau.se
Ahola-Launonen	Johanna	johanna.ahola-launonen@helsinki.fi
Aquino	Yves St. James	yves-saint-james.aquino@students.mq.edu.au
Arnason	Vilhjalmur	vilhjarn@hi.is
Arnason	Gardar	gardar.arnason@uni-tuebingen.de
Aultman	Julie	jmaultma@neomed.edu
Badcott	David	badcott@tiscali.co.uk
Barnfield	Graham	gbarnfield@googlemail.com
Beier	Katharina	Katharina.Beier@medizin.uni-goettingen.de
Benaroyo	Lazare	lazare.benaroyo@unil.ch
Bernaerdt	Jodie	Jodie.Bernaerdt@ugent.be
Borovecki	Ana	ana.borovecki@mef.hr
Caenazzo	Luciana	luciana.caenazzo@unipd.it
Calderon	Pacifico Eric	pacifico.calderon@dlsu.edu.ph
Calinas Correia	Joao	j.calinas.gp@gmail.com
Camus	Agathe	agathecame@gmail.com
Choi	Yeani	xwwjdx@snu.ac.kr
Courtright-Lim	Amanda	Courtright-LimA@cardiff.ac.uk
Crombie	James	James.Crombie@usainteanne.ca
Cutas	Daniela	daniela.cutas@umu.se
Devisch	Ignaas	Ignaas.Devisch@UGent.be
Edgar	Andrew	Edgar@cardiff.ac.uk
Ehni	Hans-Jörg	hans-joerg.ehni@uni-tuebingen.de
Eisenhut	Katharina	katharina.eisenhut@gmx.de
Ferreira	Fatima	ff.lorenajordao@gmail.com
Ferretti	Agata	agata.ferretti@hest.ethz.ch
Firth	Steve	shedlock2000@gmail.com
Fontaine	Louise	Louise.Fontaine@usainteanne.ca
Galletti	Matteo	matteo.galletti@unifi.it
Gangulia Mitra	Agomoni	Agomoni.Ganguli-Mitra@ed.ac.uk
Garcia-Barranquero	Pablo	pablogarcia@uma.es
Garcia-Miranda	Rosario	rgmiranda7@gmail.com
Gefenas	Eugenijus	eugenijus.gefenas@mf.vu.lt
Glos	Aleksandra	olaglos@gmail.com
Glotova	Elena	elena.glotova@umu.se
Gordijn	Bert	bert.gordijn@dcu.ie
Gunson	Darryl	darryl.gunson@uws.ac.uk
Guntram	Lisa	lisa.guntram@liu.se
Haesen	Sophie	sophie.haesen@unibas.ch
Haeyry	Matti	matti.hayry@aalto.fi
Hall	Katherine	katherine.hall@otago.ac.nz
Hartog	Iris	i.d.hartog@amc.uva.nl
Henriques	Augusto	henriques.augusto.ost@gmail.com
Hick	Clara	cmah201@exeter.ac.uk

Hofmann	Bjorn	b.m.hofmann@medisin.uio.no
Holm	Soren	soren.holm@manchester.ac.uk
Huppert	David	david.huppert@gmail.com
Jajszczok	Justyna	jajszczok.justyna@gmail.com
Jensen	Anita	anita@hum.aau.dk
Juengst	Eric T.	ejuengst@email.unc.edu
Kaczmarek	Emilia	emilia.kaczmarek@uw.edu.pl
Kaell	Lisa	lisa.kall@gender.su.se
Kakuk	Peter	kakukpeter@hotmail.com
Keicher	Franca	fk2346@columbia.edu
Kennaway	James	james.kennaway@roehampton.ac.uk
Kimsma	Gerrit	gerrit.kimsma@radboudumc.nl
King	Nancy	nmpking@wakehealth.edu
Kiran	Asle H.	asle.kiran@ntnu.no
Langum	Virginia	virginia.langum@umu.se
Lasker	Judith	jnl0@lehigh.edu
Lawrence	David	David.Lawrence@newcastle.ac.uk
Lazareff	Jorge	JLazareff@mednet.ucla.edu
Lin	Shin-Rou	shinrou@mail.cgu.edu.tw
Lizza	John P.	lizza@kutztown.edu
Lizza	Sofia	sofia.lizza@ehess.fr
Loosman	Iris	i.loosman@tue.nl
Mahdiani	Hamideh	h.mahdiani@uni-mainz.de
Malagrino	Ilaria	i.malagrino@unicampus.it
Mallia	Pierre	pierre.mallia@um.edu.mt
McKeown	Alexander	alexander.mckeown@psych.ox.ac.uk
Michalowska	Monika	monika.michalowska@umed.lodz.pl
Miglio	Nicole	ninicole.miglio@gmail.com
Milinkovic	Igor	igormilinkovic@yahoo.com
Miller	Jane	Jane.Miller@qub.ac.uk
Morley	Sarah	Sarah.Morley@newcastle.ac.uk
Mosteller	Timothy	tmosteller@calbaptist.edu
Mueller	Sebastian	mueller@philsem.uni-kiel.de
Muench	Nikolai	nimuench@uni-mainz.de
Neiders	Ivars	Ivars.Neiders@rsu.lv
Nickel	Philip	p.j.nickel@tue.nl
O'Brolchain	Fiachra	fiachra.obrolchain@dcu.ie
Oduncu	Fuat	fuat.oduncu@med.uni-muenchen.de
Oosting	Floor	Floor.Oosting@springer.com
Pahle	Andreas	andreas.pahle@gmail.com
Paranhos	Flavio R L	flavioparanhos@uol.com.br
Pegoraro	Renzo	renzo.pegoraro@fondazionelanza.it
Petersen	Truls	truls.petersen@bioteknologiradet.no
Pouliot	Francois	fpouliotop@hotmail.com
Premuz	Hrvoje	hrwojeprem@gmail.com

Quintin	Jacques	Jacques.Quintin@USherbrooke.ca
Rakic	Milenco	milenko.rakic@unibas.ch
Ram-Tiktin	Efrat	Efrat.Ram-Tiktin@biu.ac.il
Raposo	Vera Lucia	vera@fd.uc.pt
Rehmann-Sutter	Christoph	rehmann@imgwf.uni-luebeck.de
Rennie	Stuart	stuart_rennie@med.unc.edu
Robeson	Richard	rich.robe@twc.com
Rozynska	Joanna	jrozynska@gmail.com
Rutkiewicz	Wojciech	rutkiewicz.w@gmail.com
Saelaert	Marlies	Marlies.Saelaert@ugent.be
Sahm	Stephan	stephan.sahm@t-online.de
Sahm	Antonia	a.m.sahm@outlook.de
Sauder	Michael	michaelwsauder@gmail.com
Sawada	Aiko	aiko@lime.ocn.ne.jp
Schmidt	Kurt W.	ZEMmarkus@aol.com
Schweitzer	Wolf	Wolf.Schweitzer@irm.uzh.ch
Scott	Niall	NWRScott@uclan.ac.uk
Scott-Fordsmand	Helene	hesf@sund.ku.dk
Segers	Seppe	Seppe.Segers@ugent.be
Shandera	Wayne, X	shandera@bcm.edu
Shuichi	Kato	katos@soc.meijigakuin.ac.jp
Simm	Kadri	kadri.simm@ut.ee
Simon	Christian	christian.simon@duke.edu
Simonstein	Frida	fridas@yvc.ac.il
Smajdor	Anna	anna.smajdor@ifikk.uio.no
Solbakk	Jan Helge	j.h.solbakk@medisin.uio.no
Soniewicka	Martha	marta.soniewicka@gmail.com
Spoljar	Diana	dianaspoljar@gmail.com
Sramon	Shohel	shohelsramon@gmail.com
Stanak	Michal	Michal.Stanak@hta.lbg.ac.at
Stanier	Jessica	jessica@stanier.co.uk
Stempsey	William E.	wstempse@holycross.edu
Streeck	Nina	nina.streeck@ibme.uzh.ch
Stronegger	Willibald	willibald.stronegger@medunigraz.at
Sutrop	Margit	margit.sutrop@ut.ee
Szymańska	Paulina	paulinaszymanska31@interia.eu
Takala	Tuija	tuija.takala@helsinki.fi
Tengland	Per-Anders	per-anders.tengland@mau.se
Tu	Chun-Han	johntu531@gmail.com
Tvedt	Anders	anders.tvedt@medisin.uio.no
Tyreman	Stephen	S.Tyreman@uco.ac.uk
Uusitalo	Susanne	susuus@utu.fi
VanDyke	Amy M.	Amy.VanDyke@mchs.com
Vembar	Harini	harini.vembar@umu.se
Vidal	Susana	s.vidal@unesco.org

Vogt	Henrik	vogt.henrik@gmail.com
Vollmann	Jochen	jochen.vollmann@rub.de
Walker	Mary Jean	mary.walker@monash.edu
Weber	Alan	alw2010@qatar-med.cornell.edu
Wild	Verina	V.Wild@lrz.uni-muenchen.de
Williams	Nicola	n.williams2@lancaster.ac.uk
Williams	Nicola	n.williams2@lancaster.ac.uk
Wu	Ting Yu	tw2617@columbia.edu
Xu	Jonathan	x.jonathan@columbia.edu
Yakov	Gila	gilayak@gmail.com
Zawita-Niedzwiecki	Jakub	j.zawila-niedzwiecki@uw.edu.pl
Zeiler	Kristien	kristin.zeiler@liu.se
Zimny	Tomasz Adam	tzimny@gmail.com
Zuckerman	Shlomit	shlomit.zuckerman@gmail.com