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# **ABSTRACTS**



## Reinforcing the social determinants of chronic pain: disempowering discourses in physical therapy consultations

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Social determinants of health influence the creation and maintenance of inequalities, especially in long-term conditions like chronic pain, but interventions typically focus on patients as individuals. Physical therapists address bodily dysfunctions but place significantly less emphasis on psychological and social factors, even in approaches that claim to be 'holistic'. Interventions aim to educate patients about self-care and promote autonomous choices to adopt healthier, physically active lifestyles but the medical concept of empowerment remains rooted in assumptions about personal responsibility. Biomedical and biopsychosocial healthcare discourses rest on differing assumptions about the nature of chronic pain and validate socially ascribed roles, relationships and responses to pain. In therapies based on positivist assumptions, agency, expertise and epistemic authority are typically located with practitioners; patients adopt passive roles; and therapeutic intentions focus on pain control. In contrast, therapists who adopt holistic models of care aim to develop collaborative relationships in which expertise is shared; patients are encouraged to be curious explorers of lived bodily experiences; and therapy aims to enhance capability and function. Despite increased awareness of psychological influences, however, the phenomenological focus remains on patients as individuals; the impact of social determinants is rarely acknowledged; and function is often conceptualised without explicit links to social context.

Osteopathy is a small profession in the UK (n=5,000) and most osteopaths work in private practice with individual patients, so osteopaths have limited influence on social health inequalities at the level of institutional policy making. In this paper, I argue that detrimental social impacts of chronic pain are reinforced, unintentionally, in discourses that are co-constructed between patients and osteopaths in every consultation. This occurs when communication reinforces the concept of health as *absence of pain* through either a positivist focus on manipulating the body as object or on exploring individual subjective experiences of the self. Patients seek support they can *gain from others*. In contrast, I argue that reparative responses to potentially modifiable factors like social isolation, loss of role and unemployment can be created using a social constructionist epistemology, which acknowledges the inter-subjective embodied nature of experience and conceptualises health as the *presence of meaning*. Patients seek to explore what they can still *contribute to others*, as valued social roles and relationships contribute to sense of coherence, resilience and wellbeing. Physical interventions based on ecological models of health therefore aim to explore patients' capacities to adapt to changes in health and circumstance that may not be modifiable. This approach may minimise the impact of biographical disruption and pain-related disability on their sense of being-in-the-world and help to reconnect with social networks. This may contribute, in a small way, to ameliorating the impact of factors that are both social determinants and individual consequences.

These conclusions are drawn from a qualitative discourse analysis of manual therapy consultations and experiential learning from a cohort study (n=250) into the feasibility of expanding osteopaths' psychosocial scope of care for patients with persistent pain.

## **Cultural Aspects of Disasters**

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Disasters are characterized by a collection of cultures. By virtue of humanitarian action during a disaster, the space that this intervention occupies is a particular culture of crisis. Furthermore, humanitarian actors during emergency medical care occupy the position of the 'Other'; namely, it is the patient who represents the local cultural body. Culture/s is also an organizing principle of a disaster in determining the nature of the disaster, and individual needs and vulnerabilities.

Developing a cultural lens for the context of disasters is therefore imperative for the efficacy of humanitarian responses to the crisis.

In this paper the challenges of developing a cultural lens are explored. The first part of the paper explains why disasters have cultural aspects. The second part of the paper, then, will develop this understanding further by setting forth the two conditions for a framework of culture, namely, a reflection on the meaning of culture, and finally, the ethical principles that are necessary for the interaction of cultures and 'other' cultures during humanitarian responses to disasters.

## **Cultural Factors in Disclosure of Gender Based Violence in Afghanistan**

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Gender based violence in contexts of conflict reflects societal norms during peace. Afghanistan is a challenging context in which to analyse gender based violence due to a long history of conflict as well as particular ideologies and regimes that have reduced gender inequalities. The murder of Farkhunda in Kabul, 2015, offers a case example of the normalisation of violence against women against the backdrop of religious discourse.

Research suggests that one of the most important difficulties in preventing and responding to GBV is lack of disclosure. Even though international guidelines consider disclosure as a positive first step for both therapeutic and legal outcomes in tackling GBV, differences across cultures are significant in the willingness to disclose. Cultural factors such as shame, stigma, and understandings of nang (honour) also determine risk and vulnerabilities of individuals affected by GBV.

These aspects present challenges for the way that trauma is understood from Western psychiatric frameworks in the translation of mental health disorders such as depression and Post Traumatic Stress Disorder to mental health policy. In this paper, I reflect on cultural factors that prevent disclosure of gender based violence in Afghanistan and its implications for the provision of health and societal justice as well as considerations for global humanitarian health efforts.

## **Social and personal responsibility, reciprocity, and health-care structures**

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The division of responsibility between the individual and the society is a matter of constant debate both in political philosophy and health care reforms. How should

these responsibilities be articulated? In John Rawls' theory of justice, the division of responsibility is addressed by considering the society as a fair system of cooperation accepted by all. Thus, theoretically, the idealized notion of personal responsibility lies in reciprocity: it is reasonable to expect that citizens want to contribute to the basic structure of society. Personal responsibility is, more or less, implicitly assumed. This tacit conception is well justified, taking into account that Rawls' theory concerns the necessary principles for the basic structure of a just society. Moving to a notion that clearly explicates the responsibilities inherent in the basic structure, however, opens a door for criticism. What counts as reciprocity and will everyone want to participate? Egalitarian claims for universal and unconditional welfare structures have been accused of enforcing diminished agency and free ridership. Even though these accusations might be simplified, it seems that the articulation of some sort of personal responsibility – be it moral rather than consequential – is a legitimate claim.

The more detailed discussion on reciprocity entails concepts such as “doing one's bit” by making a productive contribution to the community (if sufficiently fair economic arrangements prevail), and non-reciprocity, that is, taking advantage of the social responsibility without fulfilling one's productive contribution. Furthermore, the amount of expected productive contribution is made relative to societal position: the more the society is able to provide social rights and opportunities for productive contribution, the greater the citizen's responsibility to fulfill her contributive obligation. In order to discuss responsibilities, the reasons for non-reciprocity must not be simplified to mere issues of choice.

In this paper, I discuss what reciprocity and non-reciprocity mean in the context of health-care structures. Can these concepts, primarily discussed in welfare structures related to unemployment and social benefits, be applied in health care? More widely, an articulation of reciprocity advances the articulation of responsibility between the individual and the society, and how the responsibility of the individual should be argued in health care reforms. I suggest that if there is a direct responsibility to be assigned to the individual, it should be a moral responsibility, rather than a consequential responsibility with outcomes possibly impairing the level of basic health needs of the individual.

### **Healthcare Reform Pandemic in the World**

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The rise of the welfare state after the Second World War took place till the structural crisis of capitalism in mid 1970s. The solution for the crisis was liquidation of the welfare state. World Health Organization promoted reform in health care. A broad spectrum of countries experienced the health reform. In one end there are countries like United Kingdom, Sweden and former socialist countries where national health system was very strong, on the other end there are undeveloped countries with very weak health system. The formula was the same and characterized with marketization and commercialization of health. This was the neoliberal approach to health system and health care. Turkey experienced the liquidation of the social state through Structural Adjustment Programs in 1980. In the last 36 years, all the governments in Turkey worked for the marketization and commercialization of health care. The only difference was the name; instead of health reform, “Transition in Health”.

Transition in Health program has made dramatic changes in financing health care, primary health care, hospitals and medical faculties. Insecure and flexible working became the main approach of employment. Ministry of Health became the biggest subcontractor employer. Out of pocket and co-payments legitimized in order to decrease the financial burden on public sector. The share of the public hospitals from the budget decreased dramatically and they are forced to become a business with revolving funds. On the other hand the establishment of private hospitals promoted and through purchasing health services with the funds of social insurance system, private hospitals replaced the public hospitals gradually. Health reform pandemic is a man made disaster. The historical, social and political background of this pandemic, the liquidation of social state and the health results of the reform approach will be discussed by using recent examples and right to health conceptual framework.

### **Obstetric violence, disciplinary power and health care ethics: a Latin-American perspective**

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This presentation deals with the serious problem of obstetric violence, from a Latin American perspective, and its relationship with the issue of power relations between health care professionals and patients. The discussion is based on the empirical findings of a qualitative research project developed in Costa Rica, during the years 2013 to 2015. The methodological strategy was based on in-depth interviews with physicians, obstetric nurses and women who received obstetric care during the last 5 years, before the publication of the national norm on obstetric health care.

The situation proved to be so dramatic that the Office of the Ombudsman took interest and opened an investigation that concluded with several recommendations for the National Health Care System (Caja Costarricense del Seguro Social). Last year, in an alliance between the University of Costa Rica and CEJIL (Center for Justice International Law), we participated in a special hearing<sup>1</sup> before the Inter-American Commission on Human Rights, regarding the situation of obstetric violence in the country.

As part of this research project on obstetric violence, I have been working on the construction of a theoretical framework that enable a more nuanced and profound analysis of the causes and consequences of obstetric violence. I have proposed the notion of obstetric power, taking as a starting point Foucault's definition of disciplinary power. I consider this theoretical tool to be useful for a critical analysis of the limits and opportunities of healthcare ethics when confronting obstetric violence, as a problem that has been so widely normalized in the medical culture.

<sup>1</sup> Here is the link to the video of the thematic hearing:

<https://www.youtube.com/watch?v=w4UuNFyGo54>

## **Moral status, “marginal cases” and the ethics of non-human primate research**

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Neuroscientific research on non-human primates contributes to our knowledge of the primate brain, including normal functions and disease. This research comes with a trade-off; we sacrifice the interests of non-human primates for human interests. Since non-human primates are phylogenetically close to us humans, their use in research is particularly problematic and contested. The Weatherall report on *The use of non-human primates in research*, published in the UK at the end of 2006, came to the conclusion that there is a strong scientific case for continuing the use of non-human primates in at least some areas of biomedical research. The report also offered an ethical justification for the use of non-human primates in research. The ten year anniversary of the report presents an occasion to revisit the ethical justification and the criticism it has received. The discussion addresses in particular the criticism, that the report’s justification would equally apply to those humans who have the same or similar cognitive capacities, and hence the same moral status, as some of the non-human primates used.

## **Ethical values as the basis of the Russian medical community**

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Russian medical ethics has an old history related to Christian principles impact on the relationship between a doctor and a patient: mercy and compassion. There were no professional doctors in Russia until the 18th century. Traditional medicine was based on treating with the help of curative herbs. The term "medicine" in our country was firstly used during the reign of Peter I. At the time St. Petersburg Medical Academy and Moscow University were founded medicine in Russia was transforming from traditional to scientific. However, the systematic course of medical ethics didn't exist before the 20th century. Norms and values of medical ethics were transferred by informal communication channels through daily contacts between professors and students in medical schools and universities and between experienced doctors and beginners. Matvey Mudrov, one of the greatest clinical therapists of the 19th century, defended the principle of confidentiality, human and professional dignity in the process of treatment. He informed patients carefully even about the worst prognosis of their disease.

Self-sacrifice, asceticism, patriotism are characteristic features of the majority of the Russian physicians. Such doctors-writers as Anton Chekhov, Mikhail Bulgakov, Vikentiy Veresayev, Sergey Botkin, Vyacheslav Manassein wrote about these principles. In the middle of the 19th century medical community discussed difficult ethical problems: preservation of medical secret, the attitude towards medical errors, norms of the equal help to the poor and the rich, an individual approach to the patient, possibility of euthanasia and others. At the beginning of 1917 there came a turning point: ideological approach penetrated medicine. In the Soviet Russia a doctor became a state servant whose activity was regulated by a set of departmental instructions. After the World War II Russian medical ethics were under influence of bioethics, which had been formed in the West.

The transformation process of moral and value basement of national medicine, in fact, was a reflection of structural changes that had affected various spheres of the society. As a result there raised a conflict between utilitarian and pragmatic ideas and high moral values in medical axiological field. So in modern Russian medicine several paradigmatic models compete: 1) traditional, paternalistic, Christian; 2) Western liberal focused on balance of the doctor-patient-community rights and interests; and 3) "economocentrism", converting medicine to business demanding fair payment for services rendered. Our research shows a difference between the attitude to a patient among experienced and beginning doctors and the value system changes. At the same time traditional ethics values remain important to modern Russian medical community.

### **Moral Failings: The Refugee Crisis in Central America**

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More than a million refugees, primarily from Syria, Afghanistan, and Iraq, crossed into Europe in 2015, seeking asylum and protection from the unbearable conditions in their homeland. The media, deeming this period as the “Refugee Crisis,” has focused heavily on the struggles faced by European peoples in trying to provide basic human needs to those entering their countries legally and illegally. Meanwhile another refugee crisis across the pond with similar ethical and legal controversies has been ignored from most media outlets, and remains unknown among many North Americans. Refugees from Central America (Honduras, El Salvador, Guatemala) are fleeing into Mexico seeking refuge from gang violence, human trafficking, and poverty, despite the fact that many living in certain parts of Mexico are also trying to leave. The United States has paid Mexico millions of dollars to stop refugees from crossing the border, or as one New York Times writer, Kate Orlinksy explains, “Essentially the United States has outsourced a refugee problem to Mexico that is similar to the refugee crisis now roiling Europe” (October 11, 2015). Humanitarian efforts are becoming more and more difficult as shelters in Mexico are becoming full, resources are being depleted, and health conditions worsen. The United Nations High Commissioner for Refugees (UNHCR) is calling on countries in Central and North America to “recognize the growing refugee situation, establish adequate capacity at borders to ensure the identification of persons in need of international protection, and move swiftly towards a coordinated regional approach.” Basic human rights are being violated, women in particular are being raped, tortured, persecuted, trafficked and murdered – yet *this* crisis is being pushed under the rug. In addressing the refugee crisis in Central America, I will specifically speak to our moral failings in recognizing and upholding basic human rights, especially health and the social determinants of health. I will look at this issue from the lens of Amartya Sen’s and Martha Nussbaum’s Capability Approach, and I will focus on those central human capabilities considered to be moral entitlements for all persons. While there is great philosophical debate regarding capabilities and whether there can actually be a central list of moral entitlements, in the context of the refugee crisis in Central America, I argue a core list that is tied to basic human freedoms is essential. Second, I argue that North America, particularly the United States, has an ethical obligation to assist in humanitarian efforts regarding this *global* crisis; it is a moral failing to simply

outsource a refugee problem without ethical justification. The United States can start by fully recognizing what is occurring in its own backyard, and create resources to ensure the safety and wellbeing of those fighting for their lives. Justice may be blind, but she doesn't turn away from basic human freedoms.

### **A critical approach to the common acceptance of Mill's harm principle in mandatory childhood vaccination**

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The moral components of medicine have been an issue since the Hippocratic Oath. Therefore, not only the provision of medical services, but also the relationship between caregivers and patients has formed a crucial area in healthcare. However, traditional medicine was largely physician-driven, requesting physicians' benevolence, whereas contemporary medicine has focused on patients' autonomy and regarded them as a decisive stakeholder in all patient-related matters. In the last five decades, the emphasis on autonomy, privacy and justice has broadened the borders of medical ethics and caused a new academic discipline to emerge: bioethics. Nevertheless, the population-based health concerns and problems have needed to transcend individual level in order to be able to protect the health of the whole population.

In this sense, public health requires a collective effort to prevent diseases, prolong life, and promote public health. It differs from curative medicine's individual-oriented position due to its population-based functions. This distinction brings about new ethical aspects. Furthermore, the protection and promotion of public health entails implementing certain ethical norms and principles to legitimize the state's interventions on individuals' freedom. As a sub-discipline of bioethics, public health ethics consists of three parties: individuals, populations, and governments. The conflicts between individuals and populations require the state to apply certain public health policies. Nevertheless, the risk of infringements in individual autonomy and interests, in case of governmental interventions to protect the wellness of population, creates ethical concerns and urges public health professionals, authorities, and scholars to explore particular moral justifications.

In this context, British philosopher John Stuart Mill's harm principle is one of the commonly used ethical principles as an approval for compulsory interventions. Nonetheless, from a liberal perspective, it is believed that Mill's harm principle does not grant exact authorization to some governmental interventions as much as it is claimed. In regard to childhood vaccination, it is scientifically proven that immunization significantly benefits individuals and all the population. However, some parents allege particular objections in accordance with their medical, religious, philosophical, and personal perceptions against vaccination. The majority of these parents merely strive to think in the best interest of their children without having any intention to harm others. For this reason, though the harm principle provides an ethical tool to the state to prevent public from harm, we believe that the grounds behind non-vaccination preclude the state from applying the harm principle to compulsory immunization.

Mill's views on liberty and individuality as well as the basic liberal values necessitate interpreting public health interventions in favor of individual freedom. The issue of whether to justify immunization programs is not the subject of this presentation. The

main thesis emphasized throughout this presentation is that authorities may evaluate mandatory vaccination the most effective way in public health policy, or the vaccination refusers' claims might be deemed entirely non-scientific and senseless. However, as long as people carry medical, religious, philosophical, or personal concerns regarding vaccination, mandatory vaccination could not be justified through Mill's harm principle.

### **Reversing the default in the social determinants of reproductive health**

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Drawing on a thought-experiment, "M's Conjecture," about the universal use of long-acting, highly effective, reversible contraception (known as LARC), this presentation explores what might be involved in reversing some of the social determinants of reproductive health—especially unintended pregnancy. It examines a series of large-scale social issues: global population growth (and decline); adolescent pregnancy, including teen pregnancy in the developed world and child-bride maternity in the developing world; pregnancy following rape, mass rape, war rape, and other sexual violence; pregnancy in maternal chronic illness and environmental exposure; and both legal and illegal abortion. Although this might seem to be a long list of serious social issues, in all of them the social determinants of reproductive health and hence health generally can—in this conjecture—be dramatically altered with one small change in contraceptive strategy. This exploration is, of course, a conjecture, not a proposal, but it is designed to show that we can think about the social determinants of health in a "default-reversing" way.

### **Surrogate Motherhood and Human Dignity – An Ethical Analysis beyond the Instrumentalization Argument**

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Surrogate motherhood is one of the most contested practices of modern reproductive medicine. Besides objections that are raised in terms of autonomy, justice and the avoidance of harm, surrogacy is often accused of violating human dignity (e.g. by the European Parliament in December 2015) – a proposition that usually results in calls for its prohibition. Advocates of this line of argument mostly argue that the violation of dignity in surrogacy results from the instrumentalization of the surrogate mother and/or the children that are born via this reproductive practice.

In my talk, I will highlight some limitations of the instrumentalization argument for criticizing surrogacy from a moral perspective. In particular, I will argue that it offers a rather superficial stance to grasp the ethical challenges of surrogacy insofar it ignores the complex interpersonal relationships and mutual vulnerabilities, which are involved in this practice. While arguing that the instrumentalization argument is not sufficient for criticizing surrogacy, I neither take this as justification for the moral innocuousness of this practice nor do I regard the perspective of human dignity as superfluous in this context. Rather, I see the need for an alternative interpretation of human dignity that is more convincing in addressing the existing ethical challenges of surrogacy than the instrumentalization account.

My thesis is that an understanding of human dignity that stresses the possibility of an acceptable identity and its respect by others (R. Stoecker) opens up a constructive perspective to address the potentially dignity-violating aspects of surrogacy. Arguing that violations of dignity specifically result from the complex relational nature of surrogacy, I will finally draw some conclusions for the handling and organization of this practice.

### **Research ethical aspects of the “psychedelic renaissance”**

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Around the millennia the number of studies on the applicability and efficacy of the so-called psychedelic substances in somatic medicine and psychotherapy – ranging from hypotheses on the possible immune-modulating role of DMT to promising preliminary results on the use of MDMA in PTSD, or LSD and psilocybin in addiction treatment – has grown significantly. Given that more and more renowned institutions (from Johns Hopkins to UCLA and the Imperial College, from the UK to Brazil) provide the background for such experiments and more and more scientific journals (e.g. PLoS One, Journal of Psychopharmacology) publish about this phenomenon often labeled as the “Psychedelic Renaissance”, I believe that these experimentations are worth investigating from the perspective of research ethics. In my presentation I attempt to provide an overview by addressing the following three questions:

- (1) Most importantly, does such research conducted on human participants (either healthy volunteers or patients) raise peculiar research ethical issues, and/or require special regulations? If so, why is it the case and what are these special issues?
- (2) Does this peculiarity stem from the special legal status and the common ethical debates surrounding the recreational, therapeutic and research-oriented use of these substances?
- (3) What relevance could these extra-scientific considerations bear on the strict research-ethical questions, if any?

Consequently, aiming to achieve a better understanding of this subject, in the following session I will present my insights on the historical context and foundations of such experiments. I will provide a critical overview of a few relevant publications on this topic, some of them describing research and innovative therapeutic application of these substances carried out in the “golden era” of psychedelic studies, some others assessing those experiments from recent research ethical perspectives. I find this “genealogical” examination pivotally important since the majority of these studies had been conducted before the Belmont Report Principles were issued and the rigorous EBM/RCT standards became widely required as the only gold standard of achieving properly robust outcomes.

Lastly, as an attempt to bridge the recent (re)emergence of this interest and the historical “starting point’s” era, I will focus on the possible reasons that led to circa three decade long break in conducting such researches (after the 1970 Comprehensive Drug Abuse Prevention and Control Act). A more comprehensive understanding of this decades-long “silence” could reveal novel things that we could learn concerning recent research ethical issues.

Finally, though I cannot dwell – due to the lack of time – into the biopolitical perspectives that could evidently chisel the overall picture, yet, I will try to briefly incorporate some surmises on what supra-scientific factors may have been impactful in this regard.

### **Ethical Compartment, Chores, and Challenges in Aesthetic Medicine**

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Aesthetic medicine is a mixture of medicine, art, and entrepreneurship. Maintaining an appropriate balance between these factors is essential to protect the well-being and to optimize the best interests of patients. The objectives of this session are (1) to present the ethical issues arising in aesthetic medicine practice and (2) to discuss the roles of and challenges faced by physicians in the practice thereof. Aesthetic medicine should go beyond the non-maleficence principle and should be seen to benefit patients positively. Enhancement versus therapy, risks and patient safety, patient autonomy, beneficence, and informed consent are timely issues that should be reconsidered and emphasized. Honest and responsible advertising and adherence to standards set by relevant professional regulators should be observed. Medical interventions that are only supposed to increase the desired, positively perceived attention from others are not necessary according to medical ethos. As an art, aesthetic medicine should feel the obligation to judiciously resist modern ideologies and should assist patients in searching a more authentic attitude towards themselves. Heightened attention to traditional duties and new attention to the proposed responsibilities of the aesthetic practitioner should enhance patient safety and empower patients in making choices.

### **Ethical challenges in the upcoming era of the environmental and ecological engineering for the public health reasons**

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Society stands in front of one of the major breakthroughs in gene editing technologies CRISPR Cas9, which, for the first time, enabled scientists to precisely cut DNA molecules that can be exploited to insert other genes or explicitly modify the nucleotide sequence at the cut sites. This new scientific breakthrough opened up the possibility for a new perspective within synthetic biology enabling the realization of the gene drive technology, which are in fact engineered and designed genes that can break typical inheritance rules and get passed to almost all of the carrier's offspring. The recent challenges from the public health perspective set out by the spreading of the Zika Virus indicated the necessity of taking into consideration as one of the measures for the eradication of the Zika virus the use of gene drive technologies on mosquitoes. Therefore, this gene editing and gene drive technology have become powerful tools for ecological and environmental engineering, through which a human can manipulate his surrounding adjusting it to himself and directly mastering the evolution and ecosystem because of numerous reasons and not only public health reasons. Within the human health domain, the gene drives might help in eradicating insect-borne diseases such as malaria, dengue, yellow fever and lately Zika virus. One of the ethical challenges caused recently by the spread of the Zika Virus is the

implementation of such technologies without proper field trials and adequate risk assessment for a responsible implementation. Unfortunately, these challenges are mostly covered under the coercive and nudging industry politics that receives above all the compassionate use in these epidemic situations. Furthermore, lack of the actual knowledge of risk management and containment associated with different gene drives decrease our ability to adequately control the spread out of these gene drives. From the technical point of view, the advantage of this technology is that it is reversible, meaning that the changes inserted with one gene drive in a population might be reversed back with the other gene drive. Moreover, in theory, this new form of gene engineering has been foreseen for the targeted populations (e.g. mosquitoes), but it remains to see the reliability of these gene drives on how they are going to stay only within these target populations without spreading out to non-target or related species through e.g. cross-breeding, which may cause unintended ecological consequences and even species extinction. In this ethical discussion is not the question whether the priority should be given to the environment or the public health, but do we need to rush into such decisions and change the entire ecological system at the moment when we do not completely understand the side-effects of the actual technology or we should use other methods for fighting and eradicating these diseases. However, the issues of ecological engineering are not only a matter of scientific or industry assessment of positive and optimistic impacts, as it has recently been presented, but it is also an issue of community engagement through transparent, informed and fully inclusive public discussions.

### **Non-invasive prenatal testing for aneuploidy – experiences and perspectives**

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In the past fifteen years, the isolation and analysis of free fetal DNA or whole fetal cells in maternal blood has been made. As a result new methods for testing during pregnancy were established. These technologies aim to offer non-invasive prenatal testing (NIPT) to provide definitive molecular or chromosomal information about the health of a fetus. From the very beginning the announcements of discovery of a new prenatal testing method has been accompanied by articulations of ethical concern. The first area of concern was the belief shared by many commentators that introduction of NIPT into clinical practice would have significant impact on patients' autonomy. Another recurring topic was the concern regarding how NIPT would change the previously established prenatal testing practice. There was also considerable number of opinions aired on possible negative consequences of NIPT on social perceptions of people with disabilities. Finally, the concerns regarding justice and equal access to the new technology were also expressed.

The aim of the presentation is to provide information on the current status of NIPT. In particular, I will provide the literature review of the implementation of and experiences with cfDNA testing, the impact it has had on the previously existing practice of prenatal testing, professional attitudes (including recently released both American and European professional guidelines as well as surveys of genetic counselors' experience, opinions, thoughts and concerns) regarding the implementation of cfDNA testing as a screening tool for aneuploidy. Finally, I will address the question whether the ethical concerns voiced at the outset of these new methods of non-invasive prenatal testing have been confirmed by the practice.

## **Empirical ethics: Using data triangulation to study the practice of informed consent by healthcare professionals in South Africa**

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**Background:** Informed consent (IC) is a legal and ethical doctrine derived from the principle of respect for autonomy. The right to bodily integrity is constitutionally protected in South Africa, while a court decision in *Castell v DeGreef* 1993 led to a shift in South African medical jurisprudence from the ‘reasonable doctor’ to the ‘prudent patient’ standard of information disclosure. The National Health Act 2003 stipulates that healthcare professionals (HCPs) must inform patients about diagnosis, risks, benefits, treatment options, and the right of refusal, in a language patients understand. Multicultural societies in Africa are inherently challenged by problems of poverty, education, language, and power asymmetry between doctors and patients; all of which could impact on IC. Here, I report an empirical study on the practice of IC in South African public hospitals.

**Methods:** This was a cross-sectional descriptive study, using separate semi-structured questionnaires for HCPs and patients. Data triangulation involved comparing responses from HCPs and patients statistically. The study was conducted at six randomly selected public hospitals in Durban, South Africa. Ethical approval was obtained from local RECs while written IC was obtained from all participants.

**Results:** A total of 927 respondents completed the study, comprising 168 medical doctors, 355 professional nurses and 404 patients. Participating doctors ranged from interns to specialist consultants with 1-55 years professional experience. Participating nurses were mostly female (92%); median age (39 years), with 1-41 years of professional experience. Patients were mostly female (68%); median age (35 years). Most spoke the local language IsiZulu (55%), were single (56%), unemployed (66%), with secondary school education (69%). HCPs spent 5-10 minutes obtaining IC from patients. Information disclosed included diagnosis (doctors = 96%, nurses = 77%); treatment options (doctors = 81%, nurses = 68%); recommended treatment (doctors = 89%, nurses = 65%); risks of refusing recommended treatment (doctors = 88%, nurses = 69%); treatment benefits (doctors = 97%, nurses = 71%); and right of refusal (doctors = 65%, nurses = 67%). Comparatively, patients were informed about diagnosis (81%), risks (57%), and benefits (61%). Fewer were informed about treatment options (41%), recommended treatment (28%), and right of refusal (25%). Respondents were unfamiliar with basic local laws such as legal age of consent to treatment, with 71% of doctors and 30% of nurses responding accurately. Majority of patients were satisfied with information disclosed (91%), did not feel coerced, few were afraid to ask questions for fear of losing free treatment (8%). Triangulation revealed inconsistencies between HCPs and patients with 25-41% of patients reporting non-disclosure about right of refusal, treatment options and risks of refusing treatment. Patients reported IC was obtained verbally in 75% of cases, while doctors claimed 51% written consent.

**Conclusions:** This study suggests that South African doctors are fairly knowledgeable about the doctrine of IC, however not all complied with the legal requirements. Major challenges regarding IC in this setting were language barriers and lack of interpreters to assist with patient communication, time constraints and heavy workload. Patient identified barriers to IC included poverty, language, and poor

education. South African patients preferred disclosure of all ‘material risks’, better communication skills by HCPs, and a shift from informed to shared healthcare decision-making.

### **Surrogacy and the Problem of Autonomy**

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Although still not legal in many countries, the practice of surrogacy is perceived as a very important issue in contemporary ethical and legal debates. Surrogacy arrangements can take many forms, depending on the origin of the gametes used (prospective legal parents or donors) or financial arrangements between prospective legal parents and the surrogate. Surrogacy arrangements can be altruistic, in which no remuneration to the surrogate is involved (except for compensation of reasonable expenses associated with pregnancy), or commercial arrangements in which the gestational mother is being paid for her service.

One of the many ethical and legal problems associated with surrogacy arrangements concerns respect for the surrogate’s autonomy in commercial arrangements. The focus of many of worries is economic and educational vulnerability of prospective surrogates. Those who organize surrogacy services and those who employ surrogates may have an advantage over her as far as resources and information are concerned. Therefore, there is a possibility of exploitation and abuse of the surrogate. The main instrument of protection of the surrogate’s autonomy that is discussed in the literature is informed consent, which has been an essential ethical and legal requirement for legitimization of medical and research intervention.

In my presentation I will focus on the problem of autonomy of women entering into surrogacy arrangements as surrogates. My main goal is to identify the components of the surrogate’s autonomy and the threats to it that surrogacy arrangements may pose. Against the background of the two elements (surrogate’s autonomy and possible threats to it), I will try to assess how informed consent protects or enhances the surrogate’s autonomy. Accordingly, I will discuss two possibilities. Informed consent, as it is understood and used today in medical and research practice, may provide sufficient level of protection of surrogate’s autonomy, or it may prove to be defective. I will attempt to delineate the mechanisms of protection and their limitations. In the remaining part of my presentation I will explore the two possibilities and try to determine how, beyond (and independently of) informed consent, the surrogate’s autonomy can be not only respected and protected but also enhanced.

### **Ethical and Legal Issues About Sexual and Reproductive Health Services in Turkey**

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To make sexual and reproductive health rights equally accessible for all individuals in Turkey, identifying ethical and legal issues about sexual and reproductive health service is important. In that report, sexual and reproductive health services in Turkey will be investigated in five main titles.

1. Protection of private life: In recent years, by the great pace of transformation of health policies, the Ministry of Health needed some regulations and laws about personal health data collection, recording, saving, share and started to do some actions about these titles. In this context, health services want patients to share many data about sexual and reproductive lives as long as they take health services. However, these regulations are criticized for being inappropriate for medical ethics and law; therefore, there are some doubts about possible violations in human rights. In addition, these policies are also criticized for hindering the utilization of sexual and reproductive services by patients.

2. Induced Abortion: Discussions about right of access to induced abortion practices have great value in the context of right of access to sexual and reproductive health services. In addition, the facts that women who want induced abortion in the legal time cannot access this service without their husbands' permission and women who have not completed the age of 18 have no right to request induced abortion without legal representative although they have the ability to decide are discussed with legal and ethical perspectives. Also ambiguity in the penal code for the termination of the pregnancy in the case of sexual assault is criticized.

3. Living with HIV: There are many ethical and legal discussions about facing discriminations and stigmatizations for people living with HIV especially in receiving medical care and services and protection of their private life. Some legal problems can be seen about refusing to treat, saving data or explanations of data for people living with HIV.

4. Under 18: There are important problems and barriers seen in taking sexual and reproductive health services in people under 18 because of legal controversies about taking their informed consent by themselves or with their legal representations.

5. Sex Reassignment: Individuals are granted the right to want to change their sex by civil laws. According to this laws, people over 18 years old, not married and infertile have right to change their sexes if they want. These conditions are criticized for both not considering individual decision-making capacity and compelling unnecessary medical interventions.

In this oral presentation, these five titles in context of ethical and legal issues in sexual reproductive health services on a range of assessments will be discussed.

### **Compassion: Necessary insights for clinical practice**

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**Background.** Compassion is an interdisciplinary theme especially relevant in clinical ethics. For centuries, compassion has been assigned a crucial role in medicine; it has not only been traditionally considered important, but fundamental to medical practice. However, some countries have recently experienced a diminution of quality of medical care, due precisely to a lack of compassion in clinicians. According to several contemporary studies, compassion is a major determinant of the patients' perspective of the quality of medical care; this same compassionate attitude would also be of benefit to the clinician, ensuring greater job satisfaction and less burnout. However, the richness of the human experience, nuances of compassion, and the partial overlap of compassion and similar sentiments (such as empathy) have made the study of compassion more complex, including its role and its determinants in clinical practice. Therefore, there is a need to reintroduce compassion within medicine, ensuring

adequate understanding of this central human attitude in medicine, along with its anthropological structure and clinical application.

**Aim.** An anthropological rooted ethical reading of the clinical experience of compassion.

**Methods.** Analysis of the dynamics of compassion according to the Aristotelian–Thomist anthropological paradigm and the characterology of the German psychologist Philip Lersch.

**Results and discussion.** Compassion is defined as “a strong feeling of sympathy for people who are suffering and a desire to help them”. Anthropological analysis of the dynamics of compassion shows that because compassion is informed by reason, it moves not only from the observation of another's suffering, but mainly from the perception of another's dignity. Emotions and feelings are not pure reactions or biological processes, but they are real human experiences that convey meanings and values. Therefore, he who has compassion suffers - because he sees an evil - but does not flee, does not avoid - because he recognizes a value. On the contrary, the perception of suffering, without the perception of that person's dignity, would cause other types of feelings (disgust, fear ...). So, when we plan to nurture the attitude of compassion, it is essential to facilitate and strengthen the perception of a good or value, which in this case will be the preciousness of the human being, even when afflicted by suffering. It is the degree of absoluteness with which one views the value of the other which marks the difference in acting compassionate.

**Conclusion.** Compassion is the human premise of each clinical act. There will be real compassion when clinicians see the man over his misery and despite its poverty. We state three main conclusions: 1) We claim an anthropological approach to understanding compassion in clinical ethics instead of only a psychological approach; 2) It is the appreciation of the dignity of a human person that causes the feeling of compassion and allows one to overcome the initial negative reaction to suffering; 3) Clinical mentorship, reflective practice, and experiential learning are referred to as the most appropriate teaching methods to develop compassion in healthcare practitioners.

## **Ethical Issues in Alzheimer’s Disease Research with Human Subjects**

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As we aggressively pursue Alzheimer Disease (AD) research, we encounter important ethical challenges. This presentation describes and analyzes ethical issues arising with AD research involving human subjects. The discussion is organized around four areas of concern: 1) large and lengthy longitudinal studies, with some subjects moving from competence to incompetence as the study progresses; 2) cohorts of “study ready” volunteers who may wait years before being assigned to a specific study; 3) adaptive (Bayesian) trial design, which is challenging to explain to subjects; 4) use of biomarkers to diagnose AD before it becomes clinically apparent, raising issues of what to tell participants. Strategies to address these concerns include centralized institutional review boards; appointment of legally authorized representatives for subjects who may become incompetent in the future; iterative consent processes; broad discussion of the benefits and drawbacks of sharing biomarker information with subjects.

None of these challenges, thoughtfully handled, poses barriers to research. But if ignored or mishandled, they could slow the research process and alienate potential

participants. Defeating AD is one of the great challenges of our time, and we need to answer that challenge on every possible front. We need to respond to the ethical issues surrounding AD (and other forms of dementia) with the same broad analysis that we gave to the Human Genome Project/Human Genome Organization, giving serious consideration to the ethical, legal, and social issues.

### **Does the experience of testicular cancer put extra pressure on the myth of the autonomous individual?**

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It is a popular idea to understand ourselves as independent autonomous individuals who have the ability to control our own lives and health by rationally choosing the right lifestyle. Men and women are considered responsible for building a successful career, being strong and fit. Being sick ruptures this ideal, as is the case for young men being diagnosed with testicular cancer. In literature, testicular cancer has mainly been investigated from a medical-clinical perspective. With this perspective, there is a risk to classify people in nomothetic categories and to neglect the lived experience of testicular cancer patients.

With an interdisciplinary research team (ethics, clinical psychology and medical oncology), we are currently conducting a study on how persons with testicular cancer experience their identity, illness, social relationships and provided care throughout and after treatment. As the aim of this research project is to explore the experiences of these patients, we opt for the Interpretative Phenomenological Analysis (IPA), making use of in-depth semi-structured interviews. This enables us to gain a phatic, situated, relational, embodied and enactive account from our participants and to unravel the role of social norms in those accounts.

In our presentation, we will start from a phenomenological perspective to investigate testicular cancer, putting the narrative of the patient at the forefront. The focus, when looking at this narrative, will be on how men give meaning to having testicular cancer. Especially since this disease defies some apparent certainties like being in control of your health, being sure to live a long and healthy life, being fertile, being masculine...

### **Autonomy, heteronomy and oughtonomy**

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For years now, autonomy has been discussed as one of the central values in health care. Understood as self-realization, it is opposed to paternalism which is conceived as an intolerable occurrence of heteronomy. Although different concepts have been developed to nuance this opposition, when it comes to health care discourse, heteronomy is still the enemy of autonomy.

In our presentation, we defend the thesis that autonomy is only achievable as heteronomy. We will argue for a theoretical framework in which heteronomy is not

the dark side of autonomy, and thus something that we should try to eliminate, but rather that heteronomy 'constitutes' autonomy. Autonomy does not begin where heteronomy ends; it can only begin if heteronomy is already involved. More succinctly: heteronomy constitutes autonomy and interferes with it. While this thesis might sound a bit banal and obscure in its design, we will explain this postulate.

We are not arguing for an expansion of the meaning of autonomy, but are attempting to conduct an analysis which lays bare the 'disrupting' attendance of heteronomy within the principle of autonomy. Autonomy does not begin where heteronomy ends, but can only begin if heteronomy is already involved. To emphasize this, we prefer to elaborate a new concept: 'oughtonomy'. As the French sociologist Alain Ehrenberg speaks about the 'tiredness of being yourself' ('la fatigue d'être soi'), the increasing freedom of individuals to live their lives as they wish generates an existential pressure that many of us cannot cope with. The 'duty' to live your life in an autonomous way may be one of the imperatives of our times, but for many of us it is a difficult task to make choices and be fully responsible for them, particularly in a medical context.

As a consequence, we also discuss the possible consequences of oughtonomy for current debates concerning health care. Our quest for a new understanding of autonomy is motivated by the concern that, although the accent on autonomy as self-realization and independence has many advantages, we should also bear in mind the countless disadvantages: the obligation to free, the consequences of individual responsibility, the negligence of the determinants of our health and existence in general.

### **International economic law: a health determinant in need of action for global justice**

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**Background:** International economic law ('IEL') comprises trade, investment, intellectual property and other international legal frameworks. IEL includes law developed under the auspices of the World Trade Organization law (such as the GATT, GATS, and TRIPS), as well as bilateral and regional trade agreements such as the TPP and TISA. This law influences the availability and cost of consumer products (including tobacco, food, alcohol, and pharmaceuticals) and government capacity to regulate for the public good. Such law also influences other determinants of health, including ownership of land, taxation systems, and provision of services (for example state versus private provision).

International economic law is, therefore, an important structural determinant of health. Over the last 30 years it has become a significant factor in increasing health (and social) inequalities.

**Aim:** To investigate how and why trends in international economic law are inconsistent with basic ethical standards of global justice; and to examine feasible changes to international economic law that would be more consistent with such standards.

**Method:** Trends in international economic law since WWII and some of the main concerns (as well as positive features) were identified. The trends were assessed in relation to theoretical approaches in global justice, such as cosmopolitan and distributive justice concepts.

**Results:** Several possible reforms to economic international law that would go some way to promoting greater global justice were identified. These reforms include:

- Reshaping the purposes of instruments of IEL to recognise the importance of goals in addition to economic development: environmental sustainability, progress on social and health outcomes and equity, and advancement of human rights including social, economic and cultural rights. The current framing of these objectives as 'exceptions' would be excluded
- Modifying dispute resolution provisions so as to ensure transparency, impartiality, and consistency with the rule of law. This would in almost all cases exclude forms of investor-state dispute strategies
- Excluding from IEL coverage all products, such as tobacco, inherently incompatible with the public good
- Explicitly protecting and preserving the governmental duty to take measures and provide services for the public good (whether by regulation, taxation, health promotion or other means)
- Clarifying relationships between IEL and other international agreements, so that law on topics including health, human rights and environmental law are not 'trumped' and effectively negated by IEL.

**Conclusions:** Modifications to IEL to be incorporated in new law, and possibly to amend current law, are feasible in principle, with aspects of the above proposals in active discussion. Alone, such modifications would not radically transform existing frameworks of international law or economic order. For that, new and stronger international human rights, health and environmental law is needed, with effective enforcement mechanisms. The reforms identified would, however, provide a vehicle for allowing IEL to make some contribution towards global justice and health equity, and would be a tangible support for working towards the United Nations Sustainable Development Goals.

### **Person-centredness and personalization: Review and analysis of two related concepts in health care organization policy**

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Personalization and person-centredness are two notions that in recent decades have developed in parallel to express wishes to individualize the design of care and align it better to fit the situation of single patients. This in contrast to standardised guidelines and treatment prescriptions based on average broad population statistical evidence with wide deviations from the mean. At the same time, their sources are markedly different. While the concept of personalization stems from a biomedical framework, primarily guiding preclinical drug-development, e.g. on pharmacogenomic grounds, person-centredness originates from a clinical care and nursing perspective, and a wish for a more "holistic" view of patients, where perspectives usually ignored in the biomedical framework are put into focus. From the point of view of health care organizational ethics, however, it is unclear to what extent these two drives towards individualization can be combined, or if they conflict at a fundamental or pragmatic level. One reason to suspect so is the classic tension between care-oriented health care ethical ideals that refuse to reduce the goals of care to biomedical variables, and a more traditional efficiency-oriented health technology assessment ideal, where biological outcome parameters are at the centre of guidelines. Another reason is the

differences between the typical ethical issues and value conflicts arising within these respective frameworks. At the same time, lately, both notions have begun to drift into the attention space of the other. For instance, a recent Cochrane report of typical person-centred approaches presents itself as being about "personalized care planning", and many recent articles on personalized medicine refer to their approach as based on a wish to accommodate to "personal values, needs, preferences" and similar expressions. This paper reviews existing literature in both medicine and related philosophy to analyze closer the meaning of the two notions, and to explore the extent to which they overlap or oppose each other, in theory or in practice, in particular regarding ethical assumptions and their respective practical implications.

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### Ethics and social determinants of health in prison

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The principle of equivalence of care is enshrined in international soft law and decisions of the European Court of Human Rights. The principle is recognized widely as a theoretical and practical tool to decide which treatment and health care approaches are ethical for individual prisoners and prison populations. The principle stipulates that prisoners should receive health care that is equivalent to care available to non-prisoner patients in the same country. The interpretation of what constitutes equivalence in a given case varies among different authors. The aim of this presentation is to discuss the role of social determinants of health on evaluations as to which treatments and health care approaches are equivalent in prison. To begin with, data on social determinants of the health of elderly prisoners from a study conducted recently in Swiss prisons are compared with data from prisons in the US. Based on these available facts, a model is proposed how knowledge about social determinants of health should be integrated in the discussion about equivalence of care in prison. Ethical arguments in favour of this model as well as arguments of opponents will be analysed in order to defend a decision-algorithm for health care personnel and policy makers to define ethical obligations in prison health care.

## **Ethical and legal considerations about the age of consent to medical intervention in sexual and reproductive health care services in Turkey**

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Consent is a major condition to consider a medical intervention as a lawful act in Turkey. There is a consensus about the necessity of the consent to have information about the medical intervention and mental capacity in order to obtain a legal consent. However, different views emerge when interpreting the legislative regulations on the age of consent to medical intervention. Some suggest that, besides two aforementioned conditions, being 18 years of age or older is required as a condition for a person to give consent to medical intervention as an individual. Others approach the issue differently by suggesting that the competence of the person to decide on medical intervention should be considered rather than a precise age limit.

**First view:** This view is based on the Law on the Practice of Medicine and Related Arts issued in 1928 and the Regulation on Patient Rights issued in 1998. This law stipulates for the permission of the legal representative for medical interventions on minors. It is argued that those under 18 years of age cannot give consent to medical intervention without the consent of their legal representatives<sup>1</sup>. The aforementioned regulation has a similar approach; however, it also designates that the minors should be informed as far as they can comprehend.

**Second view:** The second view is based on the article of the Turkish Civil Code in which competent minors are entitled to decide by themselves upon their individual rights. According to this view, deciding upon bodily integrity is considered as an individual right. Therefore, it is argued that a person with decision-making capacity can give consent to medical intervention alone, even under the age of 18.

**Discussion:** Determination of the existence of decision-making capacity would vary by several factors including the nature and the content of the medical intervention, and the development and the education of the child. Therefore, it is difficult to specify the limit of the age to decide upon medical intervention alone. Waiting for people to turn 18 on the subject of medical interventions means ignoring the biological and mental development of humans. This would entail ethical and legal discussions about the right to make a decision upon bodily integrity and health.

Sexual and reproductive health-related programs in Turkey can be cited as an example. International documents on reproductive rights demand the access of the adolescents to reproductive health care services and its promotion. Nevertheless, the inability of the competent individuals under the age of 18 to give consent to medical interventions in the absence of their legal representatives would hinder their access to sexual and reproductive health care services in delicate situations such as teenage pregnancy, access to contraceptive methods, prevention and treatment of sexually transmitted infections, and drug abuse. In this context, health care providers/institutions encounter both ethical and legal challenges. Furthermore, in the case of a requirement for the permission of the legal representative despite the capacity of a person to decide upon medical intervention, this person's right to health would be violated.

<sup>1</sup> Article 11 of the Turkish Civil Code considers all persons under the age of 18 as minors.

## **Theoretical approaches: A revisionary theoretical approach to disability: The picture theory of disability**

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This paper argues that contemporary models of disability fundamentally misunderstand the nature of disability. As a result, there is a possibility that normative claims employed in health care, welfare distribution, law, social and political policy, etc., arising out of these models may be improper, unhelpful, or even counter-productive. A revisionary approach to the phenomena of disability has resulted in the Picture Theory of Disability (PTD) — a descriptive theory of disability which may provide a better understanding of the experience of disability.

Current dominant approaches hold ‘disability’ to be nounal — the sort of thing possessed by a person, something caused by a person’s environment, or some combination of the two. In contrast, The PTD offers an adverbial account of disability and is designed to evaluate disability as an experience rather than a property someone has — there are no ‘disabled people’ or ‘disabling social conditions’, there are just persons who experience disability in the conduct of their life. The PTD asserts that disability is adverbial because the experience relates to a certain kind of negative modification of a verb — an aspect of ‘doing’ rather than a ‘something’. More simply put, current models make a category error: disability is not a ‘thing’, it is a certain kind of experience.

The PTD shows when, where, and how disability is experienced; it does so by employing elements of Wittgenstein’s Picture Theory of Language and Humean sympathy to identify the exact manner in which a verb is negatively modified. In short, disability is experienced when verbs are negatively modified to the extent that the verb is irremediably impeded. Thus, paying attention to the manner in which the verb is being modified shows how an action is being blocked for a particular person in particular circumstances. Within the PTD, the use of Wittgensteinian pictures shows how and why a person in the picture experiences what they do, and conation arising as a result of Humean sympathy helps to understand how a person in the picture might feel about that experience.

The PTD is geared to be a descriptive theoretical effort — it offers a careful analysis of how the interplay between the individual and their environment creates disabling experiences. The ethical debate about how one might best ameliorate that interplay is of paramount importance in creating both a more accepting society and greater inclusion for disabled people. But — and this must be emphasised — before such claims can be made, it is imperative that the nature of disability be properly understood.

## **Social factors and a normative core concept of disease**

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I have earlier suggested a normative core conception of disease, as clinically and socially relevant complement to medical/scientific disease concepts. According to my suggestion (in modification of the concepts of other authors as Clouser/Culver Gert, or Hucklenbroich), ‘disease’ is denominated by main criteria: premature death,

suffering, and/or dysfunction, and the main cause of these criteria is present in the organism. In order to belong to the normative core of disease, a threshold of relevant severity has to be surpassed. A state of core disease described like this legitimates and demands solidary sentiments and actions as realized e.g. in public health care systems. In agreement with A. McIntyre, this helping practice is understood as core meaning of medicine as a whole, while other (also legitimate) aspects of health care as economy and career interests are regarded as additional and more contingent institutional aspects.

In my presentation, I want to reflect on how the core concept can deal with disease entities as e.g. ADHD, that are relevantly defined by *social* dysfunction and social disapproval, which makes a main cause within the organism doubtful. I will argue that in this case, more moral demands rest on other parts of society than the healthcare system, but that there still may be a core of suffering within the organism itself that legitimates/ demands (also) medical treatment.

### **Risk sexual behavior, perceived individual responsibility and policies**

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Multiple approaches are applied to address risk sexual behaviors, from individualistic approach, focused on personal traits such as age, sexual orientation, impulsivity, sensation seeking and the like to the social constructivism which elucidates structural and gender inequalities translating into risky sexual choices. Different approaches are quite diverse in their view on individual responsibility and therefore propose various sets of preventive methods. Some of them can foster destigmatization of certain sexual choices, while others promote “war on sex” by making social attitudes towards some sexual behaviors more negative. This in result creates less favorable environment and limits access to health care. In the presentation I will propose the analysis of the assumptions about the moral subjects - their motives, range of available choices and essentiality of needs that became fulfilled in result of risky sexual behavior - and how these assumptions shape policies. Both the efficacy of interventions and their relations to ethical values and sexual rights will be presented.

### **Human Rights and the Social Determinants of Health**

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International law interprets the human right to health to include the underlying determinants of health. Section 11 of General Comment 14 of the Committee on Economic, Social and Cultural Rights, for instance, states that the human right to health includes underlying determinants of health, such as access to potable water, adequate sanitation, and access to health-related education. Such determinants of health are fairly obvious, but others are surprising and controversial. There is, for example, a growing literature correlating the health gradient and the socioeconomic gradient, though the causal relationship is still controversial. As our knowledge of the number of determinants of health increases, the scope of the human right to health increases proportionately. In international human rights law the primary duty bearers who must cope with this are states. States have the duty to realize the human right to

health by respecting, protecting, and fulfilling the right to health through progressive realization.

This expansion in the scope of the human right to health threatens to undermine the right. I argue in Part I that if the human right to health is to be a genuine right and not merely an aspirational goal it requires that individuals have legal remedies so that they can claim the right to health. Unlike aspirational goals rights empower individuals to demand that corresponding duties be performed, and this I argue requires legal remedies when the state is the duty bearer. Part II discusses the extent to which expanding the scope of the human right to health to include social determinants of health undermines the legal power of individual right holders. In general the inflationary expansion brought about by including social determinants of health within the scope of the human right to health threatens to weaken the legal force of the right as it is increasingly forced to compete with other rights and policy goals. The expansion of the human right to health also threatens to undermine legal remedies because it is often difficult to show that a specific health problem is caused by a particular determinant of health such as socioeconomic inequality or lack of education. In Part III I discuss and reject several suggestions for restricting the scope of the human right to health. In particular I reject the view that the right to health should be restricted to the right to personal medical care or that it should be restricted to a minimal core that includes some of the determinants of health such as potable water. Finally I argue in Part IV that legal remedies need to include the possibility of citizen suits to enforce state regulatory efforts to cope with underlying determinants of health and that this should include the requirement of health impact assessments. In general I construe the human right to health as a right to fair procedures in developing distribution systems that progressively realize the right to health and not simply as a right to access to particular health resources.

### **The Normative Role of Mental Illness in Health Care and Forensic Psychiatry**

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The aim of this paper is to make a normatively informed comparison of the concept of decision-making competence in the health care setting and criminal accountability with focus on issues pertaining to mental illness. Mental illness can affect competence as well as accountability in such way that the ethical and legal standing of the person in question is affected. In health care the patient may lose his/her right to autonomy and in the penal justice system the defendant may be found to lack responsibility for his/her criminal acts.

This paper will compare standard criteria used within health care to determine whether a patient is competent or not with some widely used legal criteria used in assessing legal accountability (or legal sanity). Similarities and differences in function as well as in content will be explored.

Autonomy and responsibility are values commonly associated with competence and accountability respectively. Both values are subject to controversy pertaining to their meaning and interpretation. This is particularly true when it comes to criminal responsibility, which traditionally has been justified by several different theories of punishment. To the extent that mental illness affects the ethical, legal and institutional status of a person, this needs to be clarified by the normative principles justifying the practice. If there is to be a strong connection between mental illness and the

institutional status of a person, then normative principles regulating the relevant institutions need to inform our understanding of what a mental illness is.

The relationship between competence and accountability has been explored to some extent. (Meynen 2009, 2010, 2011, Juth and Lorentzon 2010) However, the similarities and differences have not, in a systematic way, been related to the ethical values and norms that inform and shape the two kinds of institutions. Exploring the tension between ethical norms and values in relation to what mental capacities that are perceived as relevant for assigning an institutional status to a person, will improve the transparency of discussions concerning which ethical considerations that should regulate the practice as well as make clear which ethical concerns that are compromised. Furthermore, such a comparison will also provide a deeper understanding of the conceptual and normative connections between the concepts.

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#### **Socio-economic inequalities in health: a challenge to sufficientarianism?**

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As studies to socio-economic inequalities in health show, absolute income or education level can only partially explain differences in health. Differences in health are (also) due to relative social status. An answer to the question of whether socio-economic inequalities in health are unjust, thus requires that this relativity is taken into account. In this paper I explore to what extent the Rawlsian account of health justice as developed by Norman Daniels (2008), and the capabilities approach to health as developed by Sridhar Venkatapuram (2011) can cope satisfactorily with this relativity factor.

According to Daniels' approach, justice demands that so-called 'health needs' are satisfied, for the reason that health – understood in the bio-statistical sense – contributes to one's 'normal opportunity range to pursue lifeplans'. I argue that Daniels account is unsatisfactorily, because it is not at all clear that abnormal biological functioning always diminishes one's opportunities to pursue life plans, nor that normal biological functioning always protects one's opportunities. Talents and skills e.g. affect people's opportunities just as well, and so one question is why normal biological functioning should be levelled while inequalities in talents and skills need not.

Also for Venkatapuram's capabilities approach, health justice is about ensuring a basic standard, albeit not in terms of opportunities, but in terms of having access to the central human capabilities as specified by Martha Nussbaum. Although Venkatapuram's focus on human dignity and the right to health is fully appropriate in

the context of setting priorities and standards for global health justice, it seems to be of little guidance in the context of relatively stable and flourishing democratic societies, where in general human rights are respected and lived up to.

So, according to both these views, socio-economic inequalities in health within contemporary welfare states are not unjust per se, as health inequalities may persist, despite of the fact that a basic or minimum level of health is achieved. Although this commitment to sufficientarianism is attractive and need not be rejected altogether, I propose that an alternative view on health justice may be developed in line with what Elizabeth Anderson has coined 'democratic egalitarianism'. Democratic egalitarianism might offer a more adequate approach to socio-economic inequalities in relatively stable and flourishing democracies, as it takes equal social and political relationships as the central concern for justice, thereby immediately addressing differences in social status. I suggest that although Anderson herself defends sufficientarian view, the capabilities she specifies actually incline towards a more strict egalitarian distribution pattern.

### **Indeterminate ethics and health policy**

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How should scarce health resources be allocated? To what extent, and how, should unjustified inequalities be taken into account when health resources are allocated? In this paper, I argue that the most promising way to approach these questions is through a hybrid approach that on the one hand recognizes the importance of substantial principles that can be invoked to discard certain alternatives, and on the other hand presents a conception of how societies can bring determinacy to indeterminacy in a justified way.

Contemporary approaches to health care rationing can be classified into two main categories. On the one hand, there are approaches that promote substantial distributive principles. In this camp, we find proponents of health maximization, weighted health maximization, principles of need, health equality, and the capabilities approach. On the other hand, there are approaches that attempt to analyze and outline what a good, just or fair decision process looks like. In this camp, we find Habermasians, Rawlsians and others.

Whereas procedural approaches have well-documented difficulties explaining why certain outcomes are bad regardless of how they have been brought about, there are good reasons to be skeptical also toward approaches that rely too heavily on substantial principles. Allocation of health resources is characterized by uncertainties. Plausible principles are likely to be vague. And theories that present substantial principles are likely to be incomplete in the sense that the promoted principles fail to establish an ordinal ranking of all alternatives. Indeterminacy problems of this kind arise for pluralists, but there are well-known aggregation problems also within the domain of what looks like single values such as equality, and the very concept *health* actualizes the same problem: how do we put the different aspects of ill-health together so that we can assess the amount of overall ill-health?

Yet, the fact that procedural approaches fail to explain why some outcomes are bad regardless of how they have come about doesn't entail that they are useless, and indeterminacy problems don't warrant skepticism. I argue that rather than choosing between these two general approaches we ought to strive for a combination of them.

In order to analyze what such a hybrid approach ought to look like it is helpful to start by understanding better what qualities it needs to have. I present two such conditions. First, they should be able to partition the outcome space so that certain outcomes can be discarded with reference to the substantial principles alone. Second, they should explain how to establish a best alternative in the outcome space that remains after the partition process is completed, i.e. they should be able to explain how we ought to select an alternative course of action when no alternative is better than or as good as every other alternative.

This entails that different policies might be justified in different countries, and different assessments of, and responses to, inequalities might be justified in different countries. However, this might be seen as a strength of these approaches.

### **Paternalism and ‘psychic harm’**

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Some policies that look paternalistic, e.g. a requirement to wear an approved motorcycle helmet when riding a motorcycle, can also be given a possible non-paternalistic justification in terms of harm to others. In the motorcycle helmet case one can for instance point to harms that occur when persons without helmets have accidents. They impose financial costs on the health care system and thereby fellow citizens, and they impose ‘psychic harms’ on those who witness the accident and its aftermath.

In the literature it is often argued that psychic harms can be or must be discounted as irrelevant, either because they are not important, or because allowing psychic harms to count may open the door to feelings of disgust being a relevant harm when evaluating public behavior leading to potential legal moralism in public policy.

This paper will argue that there are no good reasons to discount psychic harms. They are real harms, and it is perfectly possible to distinguish between psychic harms that should count and those that should not in public policy formation.

This will be shown, partly by analyzing whether or not harms induced by a hypothetical ‘harminator’, i.e. a device that can induce the experience of a harmful state without causing any actual physical harm, should count as real harms or not; and whether a person using a harminator on another person is causing harm.

### **It’s not me, it’s you**

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In this presentation, the legitimacy of nudging is being discussed. Nudging is in recent debates an upcoming intervention that is both seen as high potential as well as a possible threat to (public) health issues. It is considered as highly potential being able to steer peoples behavior in such ways that they would consider as good – as judged by themselves - without imposing anything on them or enforcing it. It is, as Thaler and Sustein argue, a version of liberal paternalism, a gesture to change behavior smoothly, without losing the option to opt out or choose for oneself. [1] Many policy makers and health advisors think that the temptations of the unhealthy consumption and behavior of citizens will more easily be resisted (I can learn not to choose the Big

Mac [2]) and it a preferable alternative on the intervention ladder of public health interventions. [3] At the same time, nudging interventions are also being disputed for stimulating one's unconscious behavior, as this is jeopardizing free and voluntary choice, is manipulative and therefore unjustified [4] In this presentation I want to focus on the questions whether the legitimacy of nudging is influenced by considerations that are not focusing on the individual. Instead, other-regarding or context-dependent considerations might be a good reason (not) to nudge. I will use two, completely different, examples to explore the relevance of what I call 'it's not me, it's you' considerations in debates on legitimacy of nudging.

First, nudging seems to assume that individuals can choose a certain life-style or behavioral pattern, even though at the same time it builds on the fact that people are 'bad choosers' [1]. In a way, this seems a bit unfair if we know that risk factors for obesity are poverty, low-self esteem and low education. If it is true that people are 'determined' by the social context that they live in, why focus on the individual behavior, even if it is a gentle push, instead of changing social conditions in which individuals live their life. It is really me, or is it you (as society) that puts people in a certain context and that makes them responsible for it too? But if we put it the other way around: would non-obese people be willing to accept health stimulating nudges, if we know that it will condition the less off towards a healthier life style, hence will decrease health inequalities?

Or take another example: it is conceived as a professional responsibility to be immunized against influenza, and several institutions already require mandatory immunization.[5] Such immunization are motivated primarily on other-regarding considerations (to protect vulnerable patients from becoming ill). In other words, a moral responsibility is put on health care workers as professionals. Yet, the uptake in voluntary immunization programs is not always high.[6] Could nudging be a legitimate intervention to gently steer professionals towards immunization if we accept their moral responsibility to it? The result of the discussion are first building blocks in determining the legitimacy of nudging.

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**Yesterday: From Pharmaceutical Studies to Clinical Studies.**

**Today: From Clinical Studies to Pharmaceutical Studies**

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Scientific studies, the driving force of science and human welfare, harbour two crucial issues in view of ethics. First of all, a better healthcare provision for future generations, which is one of the main issues of right to health and medical ethics, is

largely dependent on clinical research to be conducted in the present time. Secondly, human health is primary consideration of medicine and healthcare, and therefore, there is a need in human subjects to participate in medical research. This fact entails, mostly, human volunteers to be included in clinical studies and, hence, it brings about ethical issues of voluntariness, informed consent.

Despite the fact that there are possibilities of incidental findings and unpredicted outcomes in scientific research, medical studies on humans can, only, produce scientific knowledge on condition that they are conducted on human volunteers whose informed consent have been obtained fully and appropriately. It is widely accepted that the ethical evaluation of research projects are indispensable to protect life, honour, dignity and safety of human volunteers, as well as to safeguard society and researchers, and to provide and sustain respect and trust in medical profession in a society. Besides these reasons, scientific research can also be ethically justified as long as it subserves the rational allocation of resources. These important determinants of ethical reasoning and justification of biomedical researches have been worded in internationally accepted universal declarations and legal regulations.

Internationally accepted ethical and legal declarations are expected to be backed and complied with local law of the ratifying countries. The local regulation on clinical researches in Turkey has been subject to so many amendments over the course of time. It is argued, in this paper that the latest the Clinical Research Regulation in Turkey, has, seemingly, been limited only to the ethical evaluation of products connected to the pharmaceuticals industry.

This paper will give a contextually critical analysis of the consecutive clinical research regulations in order to draw attention of academics and bioethicists to the flaws in the local texts which are supposed to be in compliance with the universal professional values, ethical principles and international human rights law.

### **Lobbying in the healthcare systems – a challenge for bioethics?**

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It is a truism to say that lobbying plays an important role in modern politics all over the world. It is also obvious that lobbyists have an impact on health policy, both at the national and international level (e.g. by influencing political decisions at state level or taking part in Transatlantic Trade and Investment Partnership negotiations). Health-related matters, which may become a target of lobbying include the shape of intellectual property laws or the list of reimbursable drugs – issues that are crucial for the pharmaceutical industry. However, what is not evident is how we should describe, understand and evaluate the pharmaceutical lobbying without falling into the “big pharma” conspiracy theories and simplistic explanations of facts.

There are a number of challenging questions. What are the different types of lobbying? What is the role of lobbying in democracy? Does it represent particular interests at the expense of the common good or is it rather a necessary form of communication between legislators and the society, which guarantees the balance of forces in the state? Is lobbying a tool that bioethicists themselves, through numerous bioethical associations, should use to influence the shape of medical law? Is widespread negative perception of lobbying justified? How does lobbying differ from corruption?

During the presentation the current state of ethical debate on pharmaceutical lobbying will be summarized. Theoretical and normative considerations will be enriched by the analysis of concrete examples of lobbying taken from the current political reality.

### **Beautiful theories and ugly compromises – On the uses of ethical theories in decision-making**

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How relevant are moral theories in disasters? Should we look for the advice of moral philosophers in a disaster? If one answers with a tentative yes, then still, which moral theory among the several? Based on a research project within the Disaster Bioethics COST Action IS1201, I attempt to answer these questions.

According to some scholars, the emergence of bioethics in the 1970's saved the life of ethics, as a segment of moral philosophy, as academic ethics was brought back to our everyday social sphere. Although the success of bioethics fueled a renewed interest in ethical theories, but in a fresh and challenging context of everyday conflicts, dilemmas, and issues that were usually originate from health care or hospital environments. Contrary to this applied focus of much of current ethical theorizing one would scarcely find a similar academic interest in the role and concept of compromise in the ethics of decision-making in health care. Compromise is usually regarded as a valuable concept in business, in politics, in law, but not in morality. We are successors of a philosophical tradition that sees compromise in moral issues as wrong, as it forms a danger to our moral life, as it is simply a betrayal of principles and moral theories, and as to practice compromise is to demolish our moral integrity. With reference to the work Martin Benjamin - who confronted this tradition, and introduced a positive concept of moral compromise into ethics – my paper focuses on the concept of integrity preserving compromise and its potential role in ethical decision-making in disaster settings. I summarize the major elements of the dominant view of compromise in ethics and assess its relation to ethical theorizing (theories, codes, principles). After explicating the concept of integrity preserving compromise I try to assess the potential roles it might have in disaster situations where “nothing is normal”.

### **Reforming or Reframing the Health? Presentation of Turkish Health Reform by AKP**

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This paper aims to look into the discursive frame constructed by the Justice and Development Party (AKP) and the Ministry of Health regarding the Turkish Health Transformation Program from November 2002, when the first AKP government was established, to June 2011 when AKP received the 49.95% of the votes preceded by an election campaign where the health sector reforms of AKP were strongly emphasized. The Emergency Action Plan that preceded the Health Transformation Program and included the main steps that were to be mentioned in the latter was announced by the newly formed AKP government on November 2002 following the elections. This action plan included what AKP planned to achieve in their first year in office and

covered the goals of reforms within the areas of public administration, education, privatization, taxation, the stand-by agreement with the IMF, and the health system. The proposed changes that were mentioned with respect to the health system were listed as:

- \* Abolishing the distinctions among various public hospitals
- \* Administrative and financial autonomy for the hospitals
- \* A general health insurance system
- \* A family physician model together with a solid referral system
- \* Extension of preventive medicine
- \* Stimulation of private investments in the health sector.

This paper demonstrates that the changes listed in the Emergency Action Plan, and later elaborated in the Health Transformation Program have been supported by a coherent discursive narrative by the government through which their broader discourse of “transforming old Turkey” and “bringing equality to the country” was adapted to the domain of health care. This discursive narrative was constituted around the themes of serving the people, reducing the inequalities in the health-care system and protecting the health-care receivers from the health-care providers. Health-care during the AKP governments emerged as a politically significant domain since it constituted one key discursive space where the AKP’s claims to end social inequalities and “victimizations” materialized.

By analyzing the publications of the Ministry of Health, the statements of government officials in the press, and the discourses on health care reform during the 2007 and 2011 electoral campaigns, this paper argues that the Ministry of Health in particular and the AKP government in general presented a sharp division of health-care providers (mainly the doctors) and health-care receivers and step in and define themselves as actors that bring an end to the victimizations of the receivers. This argument is supported and demonstrated through the analysis of specific issues -such as the consequences of the transfer of certain public hospitals to the Ministry of Health, introduction of compulsory service for the doctors, introduction of the general health insurance etc.- in the health sector presented in the above-mentioned sources.

### **Sexual education health disparities local culture**

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The ultra-orthodox society in Israel does not provide any education about one’s own body, protecting the body or sexual education, at any age. Sexuality is considered an unmentionable taboo. It is perceived as a negative thing that one should suppress any thought or feeling about. Children do not talk about it with adults, and young people hardly dare talk about it among themselves. Superficial explanations about sexuality are given only to couples before they are married.

The damage to children and adolescents is multifold: Lack of awareness of the human body and changes to the body while growing up. The body is perceived as an instigator of evil inclinations that must be suppressed at all cost (e.g. enjoyment in touching one’s genitals). Ultra-orthodox children and adolescents don’t know what sexual abuse is and cannot protect themselves from harm. A sex offender in an ultra-orthodox community might attack more children before being caught, because helping others is considered important. Children cannot tell the difference between normal and abnormal sexual feelings. Masturbating, for example, is considered the most

serious behavior possible. An erection is an experience that should be curbed at all cost. The lack of sexual education hurts also young couples who transition overnight from a prohibition of “Negiah” (physical contact with a member of the opposite sex) to a “Mitzvah” (commandment) to have intercourse and get pregnant as soon as possible. They get a short and focused explanation with a single purpose – having children – only shortly before they are married.

The ethical question is who decides what is in the child’s best interest: The family alone or family as well as society. Is the family completely autonomous with regard to sexual education for children? Can the state force the religious education institutions to provide sexual education which is adapted to the parents’ faith?

(Sensitive culture practice) Or can the parents decide that ultra-orthodox children should not be introduced to the principles of “sexual literacy”: Getting to know the human body and being aware of it, telling the difference between healthy and pathological feelings and behavior, and the dangers they might face if they cannot identify sexual abuse. Is there a way at all to formulate socially-adaptable children’s sexual education within the principles of ultra-orthodox Judaism?

**Reference:**

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**What can contemporary medicine learn from Galen?**

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Galen of Pergamum (129-216/7), private doctor of Marcus Aurelius, is one of the founding fathers of western medicine, if not *the* founding father. He was a famous physician at the time: he was not only known for his remarkable cure of patients and his extensive knowledge, but also for his demonstrations of anatomy, performed on living animals. Evidence-based medicine was very important to Galen and, therefore, he frequently wrote about this topic. Fortunately, he left us an impressive body of literature; his preserved writings alone amount to ten percent of all surviving literature in Greek prior to AD 350.

As late as the 18<sup>th</sup> century, his writings (such as his *Method of Medicine*) were part of the basic literature for any student of medicine. With the arrival of the new era of the ‘mechanization of the world view’, which posited that science stood entirely apart from society and ethics, and new spectacular medical research was performed – with corresponding results –, his ideas disappeared from view. However, recently Galen has been rediscovered in light of our own medical-ethical questions. He argued that a good doctor also ought to be a philosopher (trained in ethics and logic) and this point of view makes him very interesting to our own time. What can we learn from his ideas on illness and health, lifestyle, the doctor-patient relationship and holistic medicine? In my lecture I would like to answer this question.

## **The Social Determinants of Antimicrobial Resistance: A Call for a ‘Broad’ Public Health Response**

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Morbidity and mortality associated with antimicrobial resistance (AMR) has risen over the past decades with the emergence and spread of a variety of drug- and multi drug- resistant pathogens. The return to a pre-antimicrobial era threatens to destabilize modern medicine and communities if common yet presently treatable infectious diseases would once again be serious or fatal, and where much of modern medicine—including complex surgery, transplants, cancer treatments, and dialysis—would become precarious due to increased risk of serious infection. Despite decades-old awareness in medical and scientific communities, AMR is finally receiving prominent attention in national and international regulatory, advisory, and policy circles, with the publication of a number of major reports and action plans (e.g., by the European Commission, Public Health Agency of Canada, World Economic Forum, World Health Organization, and US Centers for Disease Control and Prevention). Applied ethics scholars are echoing the heightened interest in AMR and have begun articulating the particular normative dimensions of AMR and advocating for possible courses of action.

In this presentation, I focus on the public health dimensions of AMR. Drawing on Verweij and Dawson’s notion of a ‘broad’ understanding of public health, which extends beyond the ‘traditional’ focus (e.g., sanitation, infectious disease control, screening and education programs) to include an understanding of how socio-economic factors affect population health, I articulate how the dynamics of the development and spread of antimicrobial resistant pathogens are intimately linked with population health, and in particular, the social determinants of health. Proposed responses to AMR have emphasized the need for judicious use of antimicrobials in clinical and agricultural settings paired with renewed R&D efforts to develop new antimicrobials. I argue that focusing on the social determinants of health provides additional avenues for addressing AMR by attending to the broader socioeconomic conditions that have enabled, encouraged, and sustained the emergence and spread of (but also that could help mitigate) AMR. Reframing the etiology of AMR to include social determinants as primary rather than background considerations widens the scope of the problem, but in so doing, is particularly salient given that response efforts may need to focus the broad goals of prevention, mitigation, and management as solving AMR may not be possible owing to the biology of resistance.

The case of AMR not only highlights limitations to existing prevention, containment, and treatment methods for infectious diseases, but also affirms the value of adopting a ‘broad’ conceptualization of public health that emphasizes the social determinants, in addition to biological, clinical, and technical factors, necessary for individual and public health.

## **Medical ethics and patients’ rights in genetic testing and genetic counseling: analysis of health policy in the Republic of Serbia**

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**Introduction:** In the post genomic era appears a tendency for individual health care, which includes genetic information about the patient in the entire process of making medical decisions that will benefit patients and the national health system. Public genetic services are related to a number of activities connected to the diagnosis, protection, and prevention of genetic diseases with different complexity at all levels of health care.

**Aim:** The aim of the study was to review patients' rights related to genetic testing (GxT) and genetic counseling (GxC) in the Republic of Serbia and the analysis of the ethical aspects of health policy in this regard.

**Method:** For the purpose of this study was done the documentary analysis of regulatory and ethical requirements for the protection of patients' rights in connection with the GxT and GxC in Serbia.

**Result and discussion:** In the RS legislation patients' rights in receiving genetic services are protected by a variety of regulations, such as the Constitution of Serbia, Law on Patients' rights and the Criminal Code. In the Law on Prevention and diagnostics of genetic disorders, genetically conditioned anomalies and rare diseases the issue of genetic counseling as part of specific genetic services is placed into the frame of the health system. Genetic counseling is done in a medical institution where GxT is done in such a comprehensive way and without influence on the will of the person to whom the advice is given. The law gives right to inspect the result of genetic tests only to the patient or his legal representative, and a duty of communicating, saving and responsibilities, to the medicine who ordered the test. Health system of the RS should create appropriate conditions for the patients and give them a chance to know, first of all, the disease from which they suffer, and to make decisions about themselves and help themselves, and to be included in the process of the treatment.

**Conclusion:** Preconditions for the development of genetics services are organized and functional health system, available knowledge and technologies for the prevention and treatment of specific genetic conditions. The main ethical standards for public genetic services are based on maximizing the benefits, minimizing harm, respect for privacy and autonomy, and providing capital.

### **Short-Term Volunteer Health Trips; Common Practices and Host Staff Preferences**

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A growing response to the harsh reality of global health disparities is the short-term volunteer trip. Sometimes referred to as short-term medical missions (STMMs), such trips involve hundreds of thousands of people annually traveling from wealthier countries to poorer countries for a week or two of health-related activities (Lasker 2016). This practice has been increasingly subject to debate between those who believe it is very valuable in addressing unmet needs and those who consider it a form of colonialism or are worried that it is plagued by unethical practices. Yet there has been very little effort to describe the characteristics of this enterprise or to evaluate it in terms of benefits and harms. Additionally, there has been scant attention in this debate to the perspectives of people in the host countries.

This paper reports on two surveys of STMM sponsor organizations based in the U.S. in order to identify common practices and then compares these practices to the preferences expressed in interviews with staff that work with volunteers in four host countries. One survey includes 177 faith-based, educational, and NGO organizations; the second, distributed to Catholic Health Association members, includes 157 trip organizers. Interviews were carried out with 55 host country staff members in Ecuador, Ghana, Haiti, and Niger (Lasker 2016; CHA, 2014).

There were striking contrasts between reported organizational practices and host country staff preferences with regard to length of stay and recruitment and preparation of volunteers. The vast majority of volunteer trips are two weeks or less, while staff working with volunteers voiced a strong consensus that trips should last a minimum of three weeks in order for them to be valuable. The majority of organizations reported minimal selectivity in choice of volunteers and brief preparation, with a focus on practical travel advice. Host staff expressed a strong desire for choosing volunteers who have skills and humility and preparing them in language, culture, and in the nature of the projects to be carried out. Findings also revealed a lack of evaluation by sponsor organizations of the benefits of STMMs either to host communities or volunteers. Host community staff generally valued the arrival of volunteers but identified desirable qualities of programs and volunteers that would make the most difference. Results suggest that changes in sponsoring organization practices, specifically in length of stay and selection and preparation of volunteers, could greatly enhance the impact of short-term volunteer trips.

### **The social responsibility of visiting surgeons**

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Many surgeons from industrialized nations travel to operate on patients from emerging countries. The individuals are either visiting professors invited to teach a hands on course at a Hospital, or are short term volunteers in NGOs of various persuasions. In industrialized nations the demands on the social conscience of physicians are distant and diluted, not so in the developing world. The visiting surgeon (VS) is exposed to an alien social reality. Medicine is the science of the gaze (Foucault). The scope of the gaze ranges from microanatomy to macro-anatomy, and defines the nature of the physician-patient relationship. I propose; that as the patient social reality affects his/her micro and macro-anatomy, the physician-patient relationship is imperfect unless the scope of the gaze includes the patient's social reality.

The scope of the physician's gaze is defined by one of the Pellegrino contractual model. A) applied biology; the physician responsibility is centered on professional competence, B) contract for service, akin to a legal contract, C) covenant, the physician is obliged by a religious or moral code to heal, D) commodity transaction and E) social functionary, where the physician's advocacy extends beyond the specifics of the disease. Model A is pivotal, without professional competence there is no ethical impunity. Many VS fulfill their ethical commitment to the patient through impeccable professional competence. The VS controls patient selection, is strict about asepsis in the OR, discusses with the anesthesiologists the physiological parameters,

and shares with hosts his/her experience. The VS feels that his/her professional competence is proven by laboratory tests and postoperative imaging.

This approach is incomplete, biologically and ethically. Undernourishment compromises immune response and impairs wound healing. And the patient's economical situation prevents standard surgical care. In my experience a great number of patients come from distant rural areas at a great cost for them and may not be capable of returning for important postoperative follow up or to refill medicines needed for restoring physiological normality or to prevent effects secondary to the anatomical alteration implicit in surgery.

For Parfait "an act is wrong just when such acts are disallowed by some principle that is optimific, uniquely universally willable, and not reasonably rejectable". The biological principles fulfill these requirements, hence, a) for any interaction between physician and patient not securing perfect biological outcome would be wrong, b) social modifiers directly affect biological outcome. Biological parameters affected by social reality are objective and independent of any ideology and as such should be factored into bioethical discussion. Until now it has been accepted that the VS adjust the scope of his gaze according to personal vision of the world. A VS is obliged by model A, not model E, to make sure that the patient is cared well beyond his/her inpatient stay. If not prepared to take that responsibility the putative VS should not travel.

### **Commercialisation of Health Care: Deepening inequalities in health**

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A recent survey of British doctors for the British Medical Association<sup>1</sup> found two thirds were "fairly or very uncomfortable" with the independent sector provision of services for the (publicly funded) National Health Service: the most common reason given was the destabilisation of NHS services and the fragmentation of services.

The commercialisation of care that would otherwise be provided by a public sector service inevitably brings this fragmentation, to create manageable size contracts for the private sector, and to separate out those aspects of health care which the private sector perceives as profitable. These normally resolve into either non-clinical support services on the one hand, or uncomplicated elective treatment and services.

Separating these services out in practice leaves the publicly-provided service carrying the more costly burden of more complex care, emergency care, chronic care -- and all of the services and tasks which the private sector sees as potentially risky or loss-making. The training of medical and other health professionals almost always falls to the public sector, even where the trained staff are then recruited to work (sometimes under preferential conditions) for the private sector.

In most OECD countries a private, commercial health care sector already exists to cater for those with the means to pay for elective care. These services are often structured to ensure that they are completely isolated from the pressures on the public sector, obviously by price, but often also by their location in separate, small and very limited hospitals and clinics, in the wealthier areas of cities rather than more deprived, or rural locations, etc.

By contrast the poorest people, along with all those with the most severe, urgent and complex health care, remain the most dependent upon publicly-funded and provided services. The continued global "inverse care law"<sup>2</sup> means that everywhere the patients

in the greatest need of health care (the very young, the elderly, the chronic sick, the disabled, the mentally ill) tend to be those least in a position to pay a market price for it – and therefore most dependent on public provision.

The commercialisation of care, the destabilisation and fragmentation of existing public provision will therefore inevitably deepen the health divide<sup>3</sup>, while also putting at risk the proper resourcing and development of comprehensive health care for the whole population.

<sup>1</sup><http://www.bma.org.uk/working-for-change/policy-and-lobbying/funding/privatisation-and-independent-sector-providers-in-nhs-care>

<sup>2</sup>Hart (1970) and Lister (2005 and 2013)

<sup>3</sup>Marmot M (2014) Review of social determinants and the health divide in the WHO European Region: final report, WHO Copenhagen

## **The Recognition of a Right to Palliative Sedation: A Comparison of Scotland, the Netherlands, and France**

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Care for a person near the end of their life is often provided by the medical specialty of palliative medicine. This type of care can be summarised as aiming to minimise and, if possible, eliminate suffering near the end of life thereby improving the quality of living and dying. As part of this, the alleviation of pain near the end of life may be achieved through the administration of palliative sedation. However, this could have the effect of hastening the patient's death which has led to the suggestion that in some instances palliative sedation may amount to "slow euthanasia" or "backdoor euthanasia". These serious concerns mean that the manner in which palliative sedation is regulated is of great importance. This paper will examine the relationship between the human rights framework and regulations governing the practice of palliative sedation as they have developed in three European jurisdictions.

The jurisdictions to be discussed are Scotland, the Netherlands, and France. Scotland and the Netherlands have introduced comprehensive guidelines on the practice of palliative sedation which physicians are obliged to follow. These guidelines serve to define the practice of palliative sedation as part of normal medical practice and, therefore, clearly distinguish palliative sedation from euthanasia. The contents of these guidelines must respect and promote a wide range of human rights if they are to fully deliver on the goals of palliative care. As such, this paper will discuss the manner in which these guidelines reflect the influence of the broader human rights framework as set out by the European Convention on Human Rights. France is also a signatory of the ECHR but has adopted a slightly different rights based approach to the provision of palliative sedation. In this respect, France has recently introduced legislation entitled 'new rights for people at the end of life' which provides a right to request palliative sedation in certain circumstances. This paper will argue that promoting access to palliative sedation in such a manner is inappropriate in light of the broader human rights framework which provides effective protection from a lack of pain management due to the protection from inhuman or degrading treatment, the right of autonomy, and the right to physical integrity amongst other. In particular, it is argued that recognising a right to palliative sedation raises questions about the legitimacy of the distinction between specialist palliative care practices and euthanasia. This also has the potential to obscure the objectives of palliative care and

fails to fully take account of its expansive applicability over the course of an illness. Overall, this paper considers the impact which the human rights framework can have on the patient-physician relationship, maintaining the legitimacy of the distinction between specialist palliative care and euthanasia, and ultimately ensuring that the individual near the end-of-life can receive appropriate palliative care.

### **Protection of human dignity in research**

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The idea of human dignity plays an increasingly larger role in bioethical regulations. When understood as empowerment, it is an instrument of protection of autonomy and rights of persons against unwanted intrusions by others. If interpreted as constraint, it grounds ethical limits on the choices and actions of individuals, including their own choices or actions that affect them. These two aspects of protection of human dignity seem to be based on two different views of obligation. The empowering requirement of informed consent is standardly justified by respect for the subject's autonomy. This justification suggests that persons assume their obligations. However, such requirements as minimisation of risks to research subjects cannot be seen as self-assumed since they constrain decisions and actions of research subjects. Yet, both kinds of requirements are claimed to be grounded in human dignity.

Based on an analysis of international ethical guidelines, recent literature on human dignity, and Kant's ethics, I will offer an account of justification of the requirements of informed consent and minimisation of risk. On this account, human dignity is to be seen as pertaining to finite embodied rational agents whose agency is susceptible to harms or fragile. As rational capacity, it commands empowerment of research subjects, and so it requires research participants' informed consent. Since human agency is also finite, and so fragile, it needs to be protected by constraining decisions and actions of both researchers and research participants. An example of such protection is minimisation of risks to research subjects.

When understood as protection of fragile agency, respect for human dignity avoids the seeming inconsistency between justifications of some key requirements of research ethics (e.g. requirement of subjects' informed consent and minimisation of risk to them). It also explains these requirements in the way suggested by ethical guidelines. Additionally, the view makes the apparent opposition between the empowering and the constraining aspects of protection of human dignity understandable.

### **“Paid to endure”: on paid research participation, passivity, and the goods of work**

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Recent sociological work suggests that as clinical research is increasingly globalized, it is also increasingly dependent on paid participants in the developing world who treat trials as a source of income. This underscores the need to scrutinize the established practice of paying research participants. Previous ethical analyses of this practice have primarily focused on concerns about “undue inducement” and

exploitation. However, these concerns are not specific to the research setting but apply to many regular occupations as well. And like in these occupations, they can be accommodated by different regulatory measures. Thus, these concerns do not speak against paying research participants, but rather in favor of conceiving and regulating paid participation as a form of work.

This presentation explores another concern about paying research subjects that remains comparably neglected. Carl Elliott and Roberto Abadie have noticed that unlike other workers, subjects are not paid to produce or achieve anything, but rather to have unpleasant and potentially degrading things done to them. They are “paid to endure”. I discuss how morally weighty this concern is, whether it is specific to the research setting, to what extent it can be accommodated by regulatory measures, and whether it ultimately undermines the conception of research participation as work. To answer these questions, I draw on recent analyses in political philosophy on the goods and bads of work as objects of distributive justice. Thus, my presentation contributes to the ongoing shift from an individual to an institutional/structural focus in research ethics.

### **Assisted Reproductive Technologies in Bosnia and Herzegovina: Legal and Ethical Issues**

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Infertility is a global reproductive health problem. The inability to have children affects couples worldwide and causes significant psychological distress in both women and men. The World Health Organization (WHO) estimates that 7-15% of all couples of reproductive age in the world are infertile. Assisted reproductive technologies have enabled many infertile couples to attain parenthood. So, from the perspective of the person’s reproductive autonomy, a so-called “reproductive revolution” is more than justified. However, tremendous medical and technological advances in human reproduction and the development of new reproductive technologies raise profound ethical dilemmas. Not surprisingly, assisted human reproduction has become one of the central topics in contemporary medical law and bioethics.

In the first part of the paper, ethical controversies surrounding new reproductive technologies will be examined. Special emphasis will be placed on the different meanings ascribed to the term dignity in the bioethical debates. In the second part of the paper, legal and ethical framework of the assisted reproductive technologies in Bosnia and Herzegovina (BH) will be explained. In Bosnia and Herzegovina, as a complex state community, health protection is one of the exclusive responsibilities of its entities: Republic Srpska (RS) and the Federation Bosnia and Herzegovina (FBH). In Republic Srpska, the costs of two in vitro fertilization procedures per couple are covered by the RS’ Health Insurance Fund. In Federation Bosnia and Herzegovina, different practices regarding the assisted reproduction financing are registered at the cantonal level (it could be argued that an equitable access to reproductive technologies is jeopardized). The necessity of the adoption of special legislation on medically assisted reproduction in BH’s entities will be emphasized. The possibility and the ethical acceptability of the more controversial reproductive technologies introduction, such as surrogate motherhood, will be explored as well. Finally, the

possible modifications of current regulations will be suggested based on the experience of other countries.

### **Person centredness and shared decision-making in forensic care, social services and public health**

Munthe, Christian; El-Alti, Leila; Nykänen, Pia; Sandman, Lars  
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Shared decision-making and person centred care (PCC/SDM) are increasingly embraced framework conceptions on how to organise health care's interaction with patients. Although underlying ethical motivation may vary, PCC/SDM holds ideals of a greater adaption of health care to individual circumstances, and of recognising patients as collaborators in clinical decision-making. The PCC/SDM notion has migrated quickly across many areas where it is less clear how it applies, due to patients being in non-standard conditions with regard to personal capacities or care context, and detected to offer a number of peculiar ethical and practical challenges. But the migration has also reached areas with even less similarity to the original PCC/SDM landscape of somatic hospital care. In this presentation, we describe – based on commissioned and work in a Swedish context and ongoing research studies – three examples of this expansion and survey these for extra ethical complications: forensic care, social services and public health (outside of health care institutions). Each area offers peculiar extra ethical challenges for PCC/SDM, as they depart extensively from standard assumptions by, in various ways, embracing goals not built on the standard individualist assumptions of health care ethics. It is possible to implement adapted forms of PCC/SDM to these areas, but these cannot be assumed to serve ideals of emancipating, empowering or recognising individuals as persons. Rather, they have to be viewed through a lens of public goods aimed for in the respective areas. Clients and patients are entitled to be made aware of this fact, but regardless of this, the mentioned perspective-shift will pose particular challenges for health professionals. At the same time, PCC/SDM strategies may also open up for approaches to resolving these tensions and meet typical challenges that would otherwise have remained out of reach.

### **Reproductive liberty through a public health ethics lens: from individual rights to the public good of procreating populations**

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Reproductive bioethics has almost entirely proceeded within an individualist paradigm, where rights of parties are set against each other or societal interests. This paper takes some steps to analyse what happens if the ethical analysis of reproductive medicine and policy is instead approached based on public health ethical assumptions. That is, the general issues are about how society should organise itself with regard to the procreation of its population, and particular issues regarding, e.g., abortion, ART, contraception, pregnancy care, prenatal testing, etc. are analysed from that standpoint. Albeit there has been some public health ethical attention to sexual health issues, this way of approaching reproductive ethics has been ignored almost entirely, with a handful of exceptions the last few years taking account of, e.g., public expenditure on

ART and environmental concerns linked to population policy. This presentation aims to sketch a preliminary theoretical framework for a general theory of reproductive public health ethics, within which such and further attempts may be placed and critically analysed, and to compare it to the traditional formats of reproductive bioethics. A general theory of reproductive public health ethics will view reproduction as a social rather than biological process, taking place at a collective level, and its values will hence be public goods and aggregates, while notions of individual rights and interests will not be primary. This view also means that there is no basic relevant distinction to be made between procreating a population through migration and through biological reproduction. The presentation will also make some work at preparing further analysis of the obvious conflicts and tensions bound to arise between this perspective on reproduction and that of standard reproductive bioethics.

### **Egg Donation Policy in Latvia: A Case Study**

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According to Section 17 of *Sexual and Reproductive Health Law* “A gamete donor may be a healthy person: male in the age of 18 to 45 years and female in the age of 18 to 35 years.” However, this year the Ministry of Health of Latvia came up with a proposal to modify this section of the law by adding a new restriction for female donors. To be allowed to donate oocyte women must not only be of certain age but they must have given birth to at least one child as well. According to the authors of this proposal there are at least three different reasons for this additional restriction. First, this restriction will help to avoid infertility due to egg donation. Second, the fact that a woman has at least one child of her own is good evidence that her eggs are fertile. Finally, from a psychological point of view, childless women cannot have valid motives for donating their gametes. As it is clear from variety of egg donation policies in different countries the issue is controversial. But whatever one’s stance in this debate, the arguments used by the authors of the current proposal are too weak to establish the desired conclusion. In my presentation I will take a closer look to the arguments and describe, how they were used to frame the public debate of the issue.

### **Palliative Sedation Therapy As the End of Relationships**

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As the bioethics revolution has displaced the paternalistic model for medical decision-making, it is increasingly important that medical professionals communicate effectively with patients and their surrogates whether they employed the informed decision making or the shared decision making model in planning care. End-of-life care planning for terminally ill patients with pain presents some of the most profound decisions patients and their surrogates can make. And, within this sphere the choice of Palliative Sedation Therapy (PST) continues to generate ethical challenges. Patients or their surrogates can only make an informed choice that PST is appropriate if they understand its dimensions. For medical professionals to assist patients and their surrogates in making a choice about PST they must provided accurate information about this intervention. This presentation aims to provide guidance on essential

accurate information medical providers should convey about PST's clinical and ethical dimensions.

Patients and their surrogates, and possibly medical professionals, too, poorly understand the clinical and ethical implications of PST. We intend to clinically and ethically disentangle PST from aid in dying, whether understood as physician-assisted suicide or active euthanasia. Even in cases in which the medical team and patient and their surrogates agree about the treatment, though it may be emotionally difficult to discuss the dimensions of PST, it is important for all of the parties to have a conversation to insure the decision makers' understanding of the intervention is not inadequate or not supported by experience.

To clinically disentangle PST from aid in dying we will argue that the practice is in fact therapy unlike physician-assisted suicide, and so it falls within the scope of the physician's obligation to heal patients. This clinical disentanglement of PST will establish the practice as ethically permissible under certain conditions, and it will help: 1. palliative care specialists to perceive PST as part of the ethical standard of care, 2. patients and their surrogates to appreciate the difference between PST and, e.g., Physician Assisted Suicide, 3. address medical professionals, patients, and surrogates' ethical ambivalence about PST. Despite disentangling it from ethically questionable actions, PST may still generate ethical disagreement between medical professionals and patients and/or their surrogates. We intend to draw attention to two distinctive features of PST palliative care specialists must be careful to communicate: it is irrevocable and terminates the patient's relationships. Because patients and surrogates may prioritize having options or continuing relationships over relief of pain, disagreement with the palliative care specialist about what constitutes appropriate care is possible.

### **Social implications of Neuro-enhancement**

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There is a growing interest among healthy individuals in using neuro-technologies (e.g., psychotropic drugs or brain stimulation devices) to improve cognition and/or behavioral functioning. Some welcome this technology and argue that individuals should be free to do what they like with their bodies. However, neuro-enhancement is not only about free choice but may be seen as a result of increased competitiveness and social pressures. In this paper I will examine the interplay between the society and the interest people may have for enhancement. Here I will discuss questions such as, what does it say about social demands when people are willing to use enhancement to keep their place on the job market? In what way can enhancement possibly facilitate intolerance towards minority individuals or groups? Will parents have a duty to enhance children for instance with mental disabilities? Will people need enhancement to be able to compete at schools or the job market?

### **Sleep problems: a plurality of determinants and remedies**

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Sleep problems are extremely serious from a societal point of view. A substantial portion of the population in many countries suffers from sleep problems. Sleep problems may directly or indirectly cause health problems. They may have harmful consequences in terms of accidents and reduced productivity. The economic costs in society are immense. However, the causal background to sleep problems is often complex. Various determinants contribute and interact. This does not exclude that some determinants are more crucial than others in particular cases. In some cases sleep problems are caused by distinct medical disorders. In other cases they have psychosocial causes related to, for example, personal economic problems or stress at work. A special category of social determinants consists of societal activities that disturb people's normal sleep rhythms such as shift work. In these cases there is a discrepancy between an individual's body clock (a biological determinant) and the social clock (a social determinant). Given this plurality of determinants of sleep problems, a plurality of potential remedies emerges. However, what is considered to be a key determinant may vary from one case to another, and this suggests in turn that the key remedy may also vary from one case to another. In my philosophical discussion of these issues I make three proposals. First, I propose an explanatory pluralism. Different explanations are adequate in different contexts given the epistemic interests in those particular contexts. No explanation of sleep problems is the most adequate in every context. Second, I propose a kind of interactionism that recognizes that biological determinants sometimes limit social malleability. The variation in sleep patterns among different cultures and within particular societies indicates the existence of some malleability in how and when we meet our sleep needs, but the existence and function of body clocks indicate that there are certain limits to malleability. Third, I propose that in searching for ethically acceptable remedies for sleep problems we should take this explanatory pluralism and this kind of interactionism seriously.

### **“Stop violence against women!” A strong civilian platform on right to life for women and liquidation of gender-based violence in Turkey**

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Violence against women is now well recognized as a public health problem and human rights violation of worldwide significance. It is an important risk factor for women's ill health, with far reaching consequences for both their physical and mental health <sup>(1)</sup>. World Health Organization (WHO) defines violence against women as “acts or threats of acts intended to hurt or make women suffer physically, sexually or psychologically, and which affect women because they are women or affect women disproportionately”<sup>(2)</sup>. According to the Convention on Elimination of all Forms of Discrimination Against Women (CEDAW) (1979) “...any act of gender-based violence that results in, or is likely to result in physical, sexual or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life” should be ended on the basis for realizing equality between women and men through ensuring women's equal access to, and equal opportunities in, political and public life.

Yet, this issue has aggravated far more than enjoying rights in political and public life recently and transformed into a global problem threatening right to life of women who demand for their own fundamental rights and freedoms. By Istanbul Convention on

preventing and combating violence against women and domestic violence (2011), Council of Europe condemned all forms of violence against women and domestic violence; recognized that violence against women is a manifestation of historically unequal power relations between women and men, which have led to domination over, and discrimination against, women by men and to the prevention of the full advancement of women <sup>(3)</sup>.

The purposes of Istanbul Convention are to: protect women against all forms of violence, and prevent, prosecute and eliminate violence against women and domestic violence; contribute to the elimination of all forms of discrimination against women and promote substantive equality between women and men, including by empowering women; design a comprehensive framework, policies and measures for the protection of and assistance to all victims of violence against women and domestic violence; promote international cooperation with a view to eliminating violence against women and domestic violence; provide support and assistance to organizations and law enforcement agencies to effectively cooperate in order to adopt an integrated approach to eliminating violence against women and domestic violence.

As this is also a heated debate in Turkey, a civilian platform, “Stop Violence Against Women” (SVAW) was established in 2009 so as to draw attention of the public on this issue and to produce solutions in order to overcome this human right violation <sup>(4)</sup>. The Platform works compatibly with the Istanbul Convention and it aims to stop all forms of violence against women and domestic violence; to protect women from violations of right to life as well as all fundamental rights and freedoms. SVAW mainly activates to keep harmed women alive, to give victims shelter and humanitarian aid, to make them accede legal support. SVAW initiates courses for women and victims to get education on their social, political and legal rights in line with the international and local laws and regulations. By means of judicial representatives, SVAW becomes involved in courts of law to advocate victims and their relatives who have faced murder, assault, violence, threat, mutilation, restriction of freedom, insult and the like. By alerting the law enforcement forces, it demands justice and legal protection for the surviving victims. SVAW attaches importance to establish dialogue and close contact with the executive bodies such as policy makers, the Parliament, government authorities, relevant ministries, opposition party in order to make them function more effectively for protection of women from intimate violence, to enable the existing laws and regulations work more efficiently.

As a matter of fact, SVAW has taken part as a stakeholder in enactment of the “Protection of Family and Prevention of Violence against Women Law” (No. 6284) and urges the Parliament and governmental bodies to monitor the requirements of law for the benefit and protection of wronged and mistreated women. It campaigns against the punishment reduction of convicts on the basis of “good behavior”. One of the crucial functions of SVAW is its systematic recording of cases of violence of all forms against women through its official website, archives and annual reports, all to be shared with the allied stakeholders, namely the Parliament, government, ministries, policy makers, media, police forces, victimized families and the public with transparency. The Platform has been organizing all over Turkey, as well as abroad by contacting target audience by means of regular meetings, promotions at civilian, societal, educational institutions, media programs, artistic and literary activities, public protests, and so on. According to the annually kept records, the Platform states that women are murdered or injured or harmed because they start to demand their

rights and freedoms such as earning their own living, breaking up or divorcing. In 2015, the number of women who were murdered on these reasons is 303 <sup>(5)</sup>.

Regarding violence against women as a global problem, this paper will deal with the activities and functions of SVAW, as an exemplary NGO to fight for women rights by focusing on its social determinants, by alerting authorities for prevention of gender-based crimes, by analyzing this human right issue within the scope of universal bioethical principles and human rights law.

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#### **The paradox of medicalization and how to master it**

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Medicine is stuck in a grip of the paradox that makes it rather lame. Dragged by this hitch, treatment goes often in vain and even may harm (Ivan Illich). As any paradox at large, also this one rests on two conflicting statements. They cannot be reconciled with each other and neither of them can be dropped away. There is no resolution of such riddles and the only option is to interpret them.

Which are the tenets being in a clash here? The first tenet can be named ‘taboo’ and requires that the ultimate motives of the patient remain beyond the range of any medical intervention in the sense of changing them. It simply avers that doctors are forbidden to persuade patients that their meaning of life is biased or even rubbish even though in many cases it seems to be foolish. The second tenet can be named ‘manna’ because it takes seriously the fact that in humans the ultimate motive is nourishing for health: healing as well as getting sick hinges to much extent on the ultimate motive the patient pursues in her/his life. In many cases including cancer mere shift of the aim brings about either infirmity or recovery.

How to overcome this rift? Indeed, there is always necessary for physicians to know motives of patients since they must regard them in achieving informed consensus with them. And, of course, reflecting on what is erroneous and what is normal in motivation is also their duty in spite the rule that to exert any pressure on individuals is prohibited. Actually these considerations should serve to opening the question about culture at large: there are cultures with pathological features and health care professionals bear responsibility for what is going on in a given society wherefore they must participate on general discussions about its routing. Basically they should boost public health education and edification while in some cases they also have a duty either to warn against perils or even to fight against evil. Therefore to get along without philosophical bioethics is not for medicine feasible.

## **Beyond utilitarianism and individualism: the “ethics of care” and social approach for elderly care**

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Our societies are facing the challenge of dealing with an increasingly ageing population, and with a great stress on social and personal resources resulting from chronic illness, disability, and a great dependency on others. The care of elderly and disabled people is a great task for healthcare today. The concern regards not only how to provide such care adequately in terms of their physical, psychological, and social needs, but also to recognize and respond to the moral (human) duty of taking care of those people considered as “useless” by the common mentality

The global problem of ensuring elderly persons an appropriate standard of medical attention and care arises at several level: physicians are goal-oriented and they do not want to be confronted by “futility”, leading them not to be interested in situations where there cannot be a result in the cure, such as in the elderly care. The scarcity of qualified personnel and the lack of allocated economic resources to provide appropriate care result in lower standards of support. These factors, especially when combined, can easily lead to healthcare situations unable to adequately respond to even the most basic needs of the elderly.

Taking care of elderly and disabled people requires going beyond utilitarianism and individualism acknowledging the elderly person as a person, and recognizing the value of relations of reciprocal dependence. This acknowledgement stands as a first general principle and simultaneously a great challenge: to see the elderly person as worthy of being cared. Furthermore, healthcare professions must retrieve the “ethics of care” founded on the very nature of human beings, recognized as interdependent persons. This perspective reveals a profound anthropological truth: by nature, inasmuch as we are human, we are all in need of others.

This “ethics of care” seeks to advance the dimension of “taking care of the other” as a fundamental value of human existence. But also the whole social context asks to be reviewed to offer a more adequate and complete answer to the existential problems of elderly, with attention to their dignity and meaning of their life. We need to overtake the logic of “medicalization” that gives answers only on the medical level, and elaborate more integrated approaches for all the needs of elderly.

## **Medical ethics dilemmas during immigrants search and rescue operations performed by the Italian Navy Vessels**

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In the recent years the Italian Government had to face one of the greatest migrants influx coming from the nearby African coasts. The Italian Navy, supported by the Coast Guard and other military corps and ONGs, received the task to operate in the Mediterranean Sea aiding the rubber dinghies unseaworthy ex-fishing boats packed with refugees and asylum seekers escaping from the most tormented Middle East and African areas. In the 2013 was launched the “Mare Nostrum” Operation ended in 2014 and followed by “Triton”, under the aegis of the European Community

(Frontex), and other national rescue operations. These military humanitarian assistance missions still represent one of the highest responses to the thousands escaping from war, violence and poverty. During the rescue operations the navy crews often had to face several issues, especially due to the unsafe approach operations to these too filled precarious boats, often in failure, carrying injured or deaths, or, for exempt, the threat of outbreaks or explosive devices on board of these embarkations. Such naval operations pose various ethical questions declined into the multiethnic and disaster medicine with which on board medical staff have to deal. Moreover the international law environment into these vessels have to operate, the precarious peacetime scenarios and the today antipiracy task of the latest missions create additional issues. In fact, sometimes, due the presence of smugglers, these operations became also antipiracy and police ones, placing additional issues to the health operators: for instance, who aids first, the migrant or the trafficker? How to manage the different ethnic patients risking a riot on board? Physicians and nurses, operating fist to the warship motorboats approaching the rescue targets providing the early medical triage and, afterwards, performing clinical interventions on their military units, faced and still face ethical questions in their interventions. Above all the imperative task to protect the crew and the vessel, the dual obligations, being in the same time military personnel and health workers, the risk of contagious diseases, perform triage and quarantine or manage scarce resources because far from the coast or overwhelmed by a multitude of patients. The request of treatment consent, the medical confidentiality, the patient trust to medical staff depict the most relational and linguistic problems that occur with the multiethnic, cultural and religious crowd of migrants in each rescue, deserve deep moral and ethical reflections. How to relate to unaccompanied pediatric patients to avoid paternalistic solutions? How respect the different culture request in a nutshell jammed of people around the sea performing impartiality? How to approach with the psychiatric disorders presented by the most rescued? How balance security issues on board with medical decisions? How to perform research? If the surge capacity, defined as “the ability to expand care capabilities in response to sudden or more prolonged demand”, render the clinical aspect of the matter, ethical issues represent what’s beyond: how these health operators have to behave in their decision making, fighting the rise of these ethical tensions? Thinking about these medical ethics issues represent a fundamental tool to protect both health operators and the rescued people into such a hostile events that occur every day around the Mediterranean Sea.

**The right to health entails rights to equity in the social determinants of health.**

Podmore, Will

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Nations enjoy better physical and mental health when everybody can access high-quality medical care, regardless of ability to pay, when everybody has good early child care and education, good working conditions, and when there are good conditions for older people and resilient communities. The right to health entails rights to equity in the social determinants of health - water and sanitation, food, housing, healthy occupational and environmental conditions, health-related education and information, and available, accessible and good-quality health care services.

Recent US studies show that greater inequality is linked to increases in mortality rates, violent crime, poor educational outcomes, teenage pregnancies and obesity.

Richard Wilkinson and Kate Pickett proved that health and social problems are more common in countries with bigger income inequalities and that more equal societies have lower levels of mistrust, illness, status insecurity, violence and other stressors.

Harmful effects on physical and mental illness begin with adverse early life experiences. Childhood abuse, neglect, and family dysfunction in a child's environment lead to negative physical health and mental health outcomes throughout the life span. Then racial discrimination, poor education, unemployment, underemployment and job insecurity, poverty, food insecurity, poor housing quality and housing instability, adverse built environments, and poor access to health care, all impact on risk for and outcomes of physical and mental illnesses.

These social determinants lead to stress with consequent psychological and physiological pathways to disease and to poor choices and risky behaviors. The same set of causal pathways from society to the individual can have adverse effects on both physical and mental illness. Some blame poor people for their bad health and poor behaviour. The evidence is that social environment constrains choices and behaviours. In *'The health gap'*, Sir Michael Marmot concluded that relative social disadvantage makes the great majority of us, all other than the very richest, suffer worse health and live shorter lives than we could. Overall economic policies directly affect our health. Social norms and public policies lead to inequalities in the distribution of education, wealth, political voice, and empowerment and lead to a social gradient in which those at the bottom have the least social mobility and the lowest chance to live healthy lives.

But instead the World Bank and the International Monetary Fund (IMF) have enforced spending cuts and privatisation. The Lancet-University of Oslo Commission on Global Governance for Health concluded, "these programmes have been disastrous for public health." As Marmot observed, "The idea that unbridled free markets in everything (the so-called Washington Consensus) is the way for countries to grow, develop and ensure better health and greater health equity is contradicted by the evidence." Health professionals can address the social determinants of health in clinical settings, but can make more progress by influencing policy decisions and attitudes on a population level. Health professionals must partner with other social forces to best address the social determinants of health.

### **The value of oxytocin as a moral enhancer**

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The potentials and drawbacks of oxytocin as a possible moral enhancer will be reviewed. I will argue that oxytocin can morally enhance us, but only in precisely specified circumstances. Moreover, voluntary moral bioenhancement is to be preferred to compulsory moral bioenhancement. It will further be argued that the grounding rationale for the use of oxytocin or any other substances as voluntary moral enhancers should not be the prevention of Ultimate Harm, but rather a specific sort of intrinsic value of goodness. This intrinsic value is reflected in the circumstance that being good is in an important sense very much in our self-interest in a way that is not related to Ultimate Harm prevention.

## **Learning from Nuclear for Climate. Moral ambiguities of climate related environmental risks to human health**

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Five years after the Fukushima Daiichi nuclear disaster of 2011, a report of the IPPNW (International Physicians for the Prevention of Nuclear War)<sup>1</sup> presents research about the long-term health impacts of the nuclear disaster in Chernobyl 1986. Low radiation doses seem to be much more dangerous than has been hitherto assumed.

Despite striking dissimilarities, which shall be pointed out in detail, there are some ethically relevant parallels between environmental risks from disasters in nuclear power plants to environmental risks from anthropogenic climate change. I will expand on four of them: (1) there is a temporal incongruence between agency and patiency<sup>2</sup> – risk causing behaviour and the potential harm; (2) there are strong societal interests due to the energy demand of economy, powerful interests are involved or affected; (3) there is a widespread dependency of everyday life from the use of the risk causing technology, which is morally accepted; (4) social influence (power over risk) and the chance to become a victim of harm are unequally distributed in society, which can be related to existing societal injustices and hinders risk avoiding behavior from self-interest. The comparison can also help to better understand the moral ambiguities of climate related environmental risks to human health.

Different things can be learned from a comparison of routinized technology use in these situations. (1) There is a need for independent research on the unequal health impacts; (2) an ethics based in responsibility for the vulnerable can only start from an impartial stance, but needs to be a critical voice in society that is committed to transforming society towards more justice; (3) research is needed that brings light into the socio-political routines and everyday technological regimes that contribute to climate change; (4) ethical implications of climate risk related socio-political routines and regimes need to be systematically scrutinized by a critical bioethics of climate change. The paper contains a discussion of Cheryl Cox Macpherson's paper on the bioethics of climate change<sup>3</sup> and argues that the list of issues contained in the EDCC White Paper<sup>4</sup> needs to be expanded.

<sup>1</sup>Angelika Claußen, Alex Rosen: Report: Gesundheitliche Folgen der Atomkatastrophen von Fukushima und Tschernobyl

30 Jahre Leben mit Tschernobyl. 5 Jahre Leben mit Fukushima. Berlin: IPPNW 2015

<sup>2</sup>Soran Reader: The other side of agency. *Philosophy* 82 (2007): 579-604.

<sup>3</sup>Cheryl Cox Macpherson: Climate Change is a Bioethics Problem. *Bioethics* 27/6 (2013): 305-308.

<sup>4</sup>Donald A. Brown et al. White Paper on the Ethical Dimensions of Climate Change (July 31, 2013). Widener Law School Legal Studies Research Paper No. 13-58.

## **Bringing informed consent back to reality.**

### **A qualitative study of potential clinical trial participants**

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**Background:** Modern bioethics conceptualizes informed consent to clinical care and participation in research as reasoned decision-making based upon respect for autonomy as well as individual deliberation and reasoning. However, there are

various psychological factors that interfere with informed consent procedures and thus undermine this ideal form of reasoned decision-making. It has been even questioned whether informed consent is possible at all. For Bioethics there is an apparent need to raise awareness of findings from behavioral sciences in order to first rethink and secondly redesign its concepts towards applicability in clinical settings. This research aimed to identify psychological factors that might interfere with this 'ideal' form of consent on the part of research subjects.

**Methods:** Thirty-six semi-structured interviews were conducted with stable patients who had either diabetes or gout. We investigated patients' attitudes towards participating in a fictitious first-in-human trial using synthetic biology technology. The focus was on an in-depth analysis of those explanations and themes that indicated the existence of psychological factors determining decision-making, such as cognition, emotions and visceral influences. For the inductive analysis of the interview data thematic analysis was applied, thereby not using a pre-existing theoretical framework.

**Results:** When analysing stable patients' attitudes towards participating in synthetic biology research, we identified three main themes that indicate how stable patients' decision-making capacity could be determined by psychological factors: a) actual and often insufficient comprehension of the inherent logic of clinical trials; b) prioritization of and recourse to trust as a key feature of patient-physician-relationship; and c) their awareness about the potency of visceral factors, e.g. pain, which might interfere with their capability to provide autonomous consent to clinical trials.

**Conclusions:** Overall, patients' responses indicate a limited psychological capacity to meet the requirements of informed consent as set by Declaration of Helsinki. In order to respect patients' and research participants' autonomy, we recommend that bioethicists and researchers need to better understand psychological factors likely to influence decision-making. In particular, a redesigned informed consent procedure should take account of these psychological realities. Norms which human beings are psychologically incapable of complying with have no value in a real world context and therefore should be used with caution in any realistic bioethical recommendations.

## **Social value and benefit sharing in international biomedical research**

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Value of research for society plays a pivotal role in justifying the exposition of human subjects to research risks. Recently, the CIOMS Working Group on the Revision of CIOMS 2002 International Ethical Guidelines for Biomedical Research Involving Human Subjects has made a proposal to consider social value a threshold requirement for ethical acceptability of all health-related research involving humans (see: project of a revised version of Guideline 1: *Social value*). Yet, both in regulatory sources and bioethical literature, there is little discussion on how social value should be understood, assessed, or balanced against research risks. Notable exceptions in this respect are papers by Freedman (1987), Karlawish (1999), Grady (2002), Casarett et al. (2002), Kimmelman (2009), Habets et al. (2014), Wertheimer (2015). However, none of these authors analyzes the concept of social value in a broader context of different direct and indirect benefits a research may bring to communities, nor

through the lenses of the Fair Benefit Sharing framework developed by the participants of the 2001 Conference on Ethical Aspects of Research in Developing Countries [2002, 2004]. Thus, their understanding of social value of research is narrow and difficult to apply, especially to international research practice.

In this paper I will present a multidimensional model of social value of biomedical research involving four dimensions, namely *scientific value* (being dependent but different from scientific validity), *health value*, *clinical value* and *community value*. I will show that this model is able to accommodate different kinds of benefits to population during and after the research, in particular those mentioned in the Fair Benefit Sharing framework (collateral health services unnecessary for research study, employment and economic activity, reasonable availability of effective intervention, research and medical care capacity development, public health measures, long-term research collaboration, sharing of financial rewards from research results). And as such, it is able to support the view expressed by numerous ethicists and researchers involved in international research that „benefit sharing is ... one of the means for promoting the social value of international collaborative health research” [Lairumbi et al. 2012: 22; Emanuel et al. 2004].

### **Justifying the risks of experimental interventions offered to Ebola patients outside the context of research**

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The Ebola outbreak that began in West Africa in December 2013 was the worst outbreak of this virus in history. It is estimated that it had caused the deaths of more than 11 300 people. Despite ongoing efforts of numerous international organizations, governments, pharmaceutical companies and scientists, there are still no therapeutic interventions against Ebola virus disease (EVD) proven to be safe and effective in humans [WHO 2016]. Only a few randomized controlled trials have been developed so far. Some of them have been already halted due to the lack of likelihood that they would demonstrate an overall therapeutic benefit; others are still in progress. However, given the very high mortality rate of the EVD and lack of proven treatment, aside from supportive care, several untested medicines have been administered to Ebola patients on a so-called “compassionate use” basis. In August 2014 an Advisory Panel of the WHO affirmed that in “the exceptional situation of the current Ebola outbreak, there is an ethical imperative to offer the available experimental interventions that have shown promising results in the laboratory and in relevant animal models”, provided they meet certain ethical, scientific and pragmatic criteria [WHO 2014]. Numerous commentators have agreed with the Advisory Panel’s position [Adebamowo 2014; Folayan et al. 2014, 2015; Goodman 2014]; others opposed the view [Hantel et al. 2014; Joffe 2014, 2015; Rid & Emanuel 2014; Shah et al. 2015].

In this talk I would like to discuss the question: what makes offering unproven interventions to Ebola patients an ethical imperative? I will analyze three groups of arguments for compassionate use: (1) arguments based on the principle of beneficence – duty to rescue; physician’s professional duty to care; compassion [Ruderman et al. 2006; Edwards 2013; Walker et al. 2014]; (2) arguments referring to the principle of respect for persons – autonomy; primacy of human being [Dresser 2015; Darrow et al.

2015]; and (3) arguments based on the principle of justice. I will argue that none of the principles and arguments provides a sufficient justification for offering an unproven, experimental intervention to Ebola patients outside the research context.

### **Incidental findings: an opportunity for autonomy or a case of hidden heteronomy?**

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Genetic testing is expanding at high speed. Whole Genome Sequencing (WGS) permits detecting mutations in the entire human genome, resulting in a better diagnosis of (rare) hereditary disorders and a more accurate personalized medicine. However, sequencing the whole genome can also reveal medical information a patient did not ask for, the so-called “incidental findings” or “surprise discoveries”. The consequences of these supplementary detected mutations can vary from disorders with a mild pathological phenotype to severe illness.

The wide spectrum of incidental findings and their different implications (chance of developing the disorder, pathological impact, time of onset, treatability, ... of the disorder) raise the question of when incidental findings are good to know and when they better stay undisclosed. Incidental findings can be an opportunity for enhanced autonomy but can also lead to more heteronomy, where suddenly revealed risks turn a person’s life upside down and have a substantial impact on the future actions and decisions (s)he makes during his/her lifespan. Therefore we should raise the question when and how incidental findings do provide an opportunity for relevant and (in multiple meanings) useful knowledge and when they mainly generate uncertainty, resulting in fear and worries.

Moreover, we should wonder who is qualified to make this distinction: patients themselves, who are probably most capable to evaluate their own situation or genetic experts and counselors, with education and expertise in interpreting incidental findings and their consequences?

We will present the outline of our qualitative research project, in which we try to answer all of these questions, and we will illustrate its twofold design. On the one hand, we will empirically investigate the current practice, lived experiences of patients and advice of experts concerning genetic testing and the return of incidental findings in a clinical context. We will realize this by in-depth interviews with patients, physicians, genetic counselors, ... On the other hand and by a more normative reflection, we want to consider these different perspectives in the context of ethical notions such as patient autonomy, personal responsibility and medical paternalism concerning genetic knowledge. This way, we want to contribute to the development of a best practice in one of the most challenging disciplines in current medicine.

## **Individual Rights versus Public Health Interests in Epidemics: Towards a Decision Making Framework for Sub Saharan Africa**

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Public health decisions made by the state involve considerable disagreements on the course of actions, uncertainties and compromises that arise from moral tension between the demands of civil liberties and public health goals. With such complex decisions, it can be extremely difficult to arrive at the best option, let alone justify it. In this article, I argue that moral philosophy in itself is not an adequate tool for those with responsibility for decision-making in infectious disease emergency situations. Policymakers require better ways to make ethical public health decisions; they need to be able to recognize an ethical issue, obtain facts about moral judgement, evaluate moral motivation or character, make a decision and, if possible, test this decision or reflect on the potential actions. A decision making framework that can be used to aid and study the ethics of responding to urgent health problems is proposed using examples of Ebola, pandemic influenza and tuberculosis in Sub-Saharan Africa. According to this approach, decision-making processes taking the form of reasoning and justification should not only consider the ethics advocated in public health and medicine, but should be reasoned within the socio-cultural and political settings supported by facts and values of all concerned. The model is deliberative and democratic in nature, focusing on contextual issues that arise in public health.

## **What do we Owe Each Other? Individualism and the Right to Health (care)**

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Many debates in healthcare, both in Europe and America, relate to the question of personal vs. social responsibility: how much should a person be made to bear the consequences of his or her own actions? In financial terms, how much cost must the individual carry? A better way of framing the debate, I propose in this paper, would be to begin with a different but closely related question: “how much do we owe each other?” Phrasing the question this way produces no easier answer, but it may help reveal why the matter is so difficult. I propose a large part of this difficulty springs from our history of individualism in the west. Many westerners tend to derive their identity primarily on the individual level, and only secondarily think of themselves as member of a group. Multiple aspects of our culture encourage this. We are urged to express ourselves, to resist conformity to groups that may seek to subsume us. I may pursue my own self-interest first (Adam Smith), pursue “my own good in my own way” (JS Mill). And we feel that it is precisely this exercise of autonomy that most expresses our humanity: “nothing is worse than to treat [me] as if I were not autonomous” (Isaiah Berlin). Much of our legislation supports this, and is designed to protect us from each other (you may not perform surgery unless I have consented). Of course, individuals may choose to come together as a group. However, in coming together, we would do it on our own terms. If the groups asks too much of me, I can pull back into the safety of myself.

How would such an individual answer the question “how much do we owe each other?” Are we surprised if the answer is “we owe each other nothing”? On what basis would I have any obligation to you, even to respond to your needs?

I propose the above discussion is related to our difficulty with agreeing whether health (or healthcare) is a right. If it is a right, it is a powerful positive right that implies a duty on the part of someone else—requires someone else to act. Yet how could you require me to act? I owe you nothing. Here is an impasse. For in the act of limiting how much I respond to you, I limit how much you can request from me. The powerful force of autonomy collides with the call to social responsibility.

In daily life we know we are interdependent. Life is not just about erecting fences to protect ourselves. We owe each other “something.” But on what basis can we say so? Can we agree about that basis? We do act and interact, and (even in healthcare) things get done. But unless we agree about why we are more than fundamentally separate individuals, we will not have the conceptual equipment to talk about how things might have been done differently.

### **Why does one medical condition in particular exemplify issues of distributive justice for the medical care system in the USA?**

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Undocumented immigrants are subjected to compromised medical care in many countries. In the USA their condition is complicated by their exclusion from benefits through the Affordable Care Act (“Obamacare”). This results in local providers of care, typically urban hospital districts, having to provide care for the undocumented.

One disease state, end stage renal failure requiring dialysis, in particular, exemplifies the problems with this dichotomy in care. What are the characteristics of this medical state that make it such a stigmatizing condition among undocumented American immigrants and such a prototypic example of problems with distributive justice?

First, the costs of care, with annual hemodialysis approach 90,000 USD per patient per year. Charity clinics can rarely incur these costs and thus government institutions to provide such care. Rarely a city/state will modify laws to broaden the scope of benefits for the undocumented (eg, in Los Angeles/California, the undocumented with renal failure are given medical benefits of indigent California citizens). Most communities however cannot afford provisions this level care and in one large, relatively wealthy city (Houston), a community dialysis center has been set up to provide services at local government expense to this population.

Second, the prevalence of end stage renal disease is relatively high in young, working populations (which most immigrants reflect), and thus with 438000 persons in the USA with ESRD, the prevalence is 1347 per million, a rate that has grown considerably over the last 30 years. With an undocumented population of over 11 million in the USA, the equivalent number with ESRD is an estimated 14,817 individuals. Equivalently expensive diseases such as cancer with attendant therapy show an older age distribution and may become an issue for the care of the undocumented as well as cohorts of immigrants age.

Third, the ultimate remedy for end stage renal disease, transplantation, remains a financially infeasible option among the undocumented. The costs for renal transplantation from one month before transplantation through the surgery until 6 months after transplantation average over are documented at up to 330,000 USD per

month, with subsequent medication costs alone 17,000 USD annually. For facilities caring for the indigent, the payments for a transplantation and related costs (at least 2.5 million USD a year) are so high that the same amount of money could be used to provide hemodialysis for a year to at least 27 patients with ESRD.

These three arguments outline why the care of ESRD among the undocumented has become a classical example of ethical imbalance using the principles of distributive justice. As diseases become more expensive in their idealized management, more prevalent as populations age, and as the alternatives for curative management provide no cost-equity solution, other conditions besides ESRD may similarly exemplify the problems of distributive justice seen among the American undocumented population.

### **Ethical issues associated with the global epidemic of diabetes**

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**Background:** With a global prevalence of 6%, over 250 million persons suffer from diabetes. Its diagnosis, interventions and prevention raise a number of ethical issues. The populations of Latin America, Africa, and East/South Asia may witness over 200% increases in the prevalence of diabetes between 2000 and 2030.

**Methods:** A review of ethical issues associated with types 1 and 2 diabetes mellitus over the last ten years, through PubMed and Google Scholar resources with compilation of articles using both terms “diabetes” and “ethics” within the title followed by a review of societal ethical issues associated with diabetes.

**Findings:** The title of few peer reviewed medical articles addresses the ethical dimensions attendant with diabetes. Among 11 such articles, 3 dealt with infants and children, 2 with the elderly, 3 with prevention and screening, 2 with hematologic stem cell transplants, 2 with driving motor vehicles, and 1 each with pregnancy, consumer protection, and cardiovascular prevention. Research ethics are the focus of 5 articles in the prior decade.

Ethical issues are a responsibility that exists at many levels of care for the diabetic. First, society is required to consider the consequences of marketing. For example there may be a need to repackage foods to promote lower consumption (to prevent or control type 2 diabetes) and to offer incentives, through taxes or insurance, to promote a healthier life style with increased levels of physical exercise.

Second, research investigators must understand the need for better genetic markers for the disease along with the risks of screening infants which include disclosure. Placebo studies are inappropriate when the hazards associated with placebo trials when blood sugars remain inadequately controlled. Better studies attendant with issues related to adherence are also needed.

Third, providers must understand their obligation to periodically learn about new therapies, to be aware of the spectrum of side effects associated with all forms of therapy, and to convey these clearly too patient populations. A current discussion in the US concerns the frequency with which control of diabetes need be assessed by the serum testing of the percent glycosylated hemoglobin.

Fourth, individual patients must recognize the importance of adherence to therapy, know the spectrum of side effects of all therapy, be enabled to make fully autonomous decisions about therapy,, and maintain communication with a staff of providers which includes nutritionists and behavior management specialists.

**Conclusion:** The paucity of entitled “ethical” articles in the literature associated with diabetes suggests that larger societal, ethical dimensions of this disease are not given primacy in the medical literature. The current outbreak of diabetes is of global consequence and it can only be controlled by the concerted efforts at societal, investigator, provider, and patient levels. Goals for improvement in indices are needed for each level of management.

### **Ethics and Social Determinants of Health**

#### **On genetic enhancement and the artificial womb**

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Editing the germ-line to improve future people's health may concord with public health goals; it may improve the health of individuals, communities, and, if successful, it may also be considered a public good. However, enhancing future generations will require IVF. This begs the question whether *all* women would have to conceive with IVF.

Remarkably, the necessary involvement of women in an enhancing scenario has not been discussed. However, the present discourse about moral obligations to future generations – although not referring to women's role – seem to imply that women could be required, morally, if not legally, to reproduce with IVF.

Enhancing future generations will be gendered; unless the artificial womb is developed. This requires a wider social perspective - of both women and men - on the issues involved. Certainly there is an urgent need for open discussion about the merits and risks of human genome modification; but this debate must include the necessary role of women in this scenario.

### **Organ Donation for Transplantation in Bangladesh: Why Family-Oriented?**

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The policy and practice of living organ donation for transplantation in Bangladesh is family-oriented: only a close relative is legally allowed to donate organs to a patient. This study examines the following policy and ethical questions: what have the family-oriented biomedical policy and practice in Bangladesh been and what are the people's views on them? How have the Islamic cultural factors and socio-economic realities of the country shaped the family-oriented character of its biomedical policy and practice in the country? And what reforms are necessary for such policy and practice and how can such reforms be ethically justified? In order to defend the policy suggestion and normative arguments of my study, I interviewed 25 transplant physicians and nurses, health administrator, organ donors and recipients, and their family members in the major transplant hospitals and institutes in Bangladesh. I also surveyed 102 people to know the broad opinion about the biomedical policy and practice. This ethnographic study reveals that the close relatives are always encouraged to donate organs for transplantation in practice for their patients, and saving the lives of close relatives by donating organs to them is understood as a moral injunction and obligation. Many view that saving the life of a close relative by donating one's organs is equivalent to saving one's own life. However, my fieldwork and participant observation have also

been discovered that potential donors may not always be available from inside families because some patients may not have close relatives or even if they do, those relatives are not medically suitable for transplantation. This indicates that a legal reform allowing non-close relatives (such as the first cousins) to donate organs is necessary and should be considered. These policy reforms are supported by the Islamic cultural and the socio-economic characteristics. The study argues that the family-oriented character of the policy and practice of living organ donation for transplantation is necessary in Bangladesh; otherwise organ selling will increase in the country where the majority of people still live on less than \$2 a day. If Bangladesh extends the current biomedical policy beyond blood relatives, it may place poor Bangladeshis in markets as daily commodities. That would be an immoral practice that should not be permitted. However, the study argues that since non-close relatives such as first cousins are also blood relatives to patients, allowing them to donate organs will not cause an organ trafficking problem as long as proper regulations are implemented. The motivation of non-close blood relations and a suitable thank-you subsidy may encourage them to donate organs to patients. My bioethics study concludes that the family-oriented character of the policy and practice is morally defensible and that the proposed remedy is also necessary and justifiable as it will improve healthcare outcomes, promote altruism and solidarity of Bangladeshi families, and protect poor people from selling their organs.

### **Developments in the practice of physician-assisted dying: views of experts**

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**Background and aims:** Euthanasia and physician-assisted suicide (EAS) have been legally regulated in the Netherlands in 2002. Since then, the way the law has been interpreted and practiced could have changed. Our study aims to describe important developments in the field of EAS since the enactment of the law in the Netherlands according to experts of the field and studies the question if euthanasia has become a normal practice and the ethical implications concerned with this.

**Methods:** A qualitative study with semi-structured in-depth interviews was conducted. We interviewed 12 experts in the field of EAS in the Netherlands, these included ethicists, policy advisors, health law jurists and researchers.

**Results:** When asked about developments, interviewees mentioned that EAS has become a more discussible topic than it was before. There is an increase of advance care directives concerning euthanasia and an emphasis on the notion of self-determination and avoidance of suffering. The interviewed experts were not in agreement whether or not the pressure to perform EAS towards physicians had increased. They mentioned the extensive debate on EAS based on psychiatric suffering or cognitive decline; while physicians are still very hesitant to perform EAS in these cases, the general public has a more liberal point of view and supports this option in general. The start of the End-of-Life Clinic – an initiative to help patients whose request for EAS was rejected by their own physician – was also seen as an important development. The interviewees said that most of the developments they mentioned contribute to EAS becoming an overall accepted practice in the Netherlands. Still, considering an actual individual request of EAS remains something out of the ordinary for physicians.

**Discussion and conclusion:** Our study shows an increased acceptance of EAS in general, but a separation between physicians and the public when it comes down to supporting more uncommon reasons to request EAS. Does this have any implications for the practice of EAS? Can the work of the End-of-Life Clinic bridge the gap between the public and physicians or only widen it further? How do these issues relate to medicalization and normalization?

### **Why the Right to health matters in Bioethics?**

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During the last thirty years we witness the evolution in the field of bioethics - from traditional medical ethics that was mainly preoccupied with physician patient relationship towards health systems and policy ethics & human rights and society ethics (determinants of health). Right to Health, as the moral ground of contemporary bioethics helped us to stress the issue of social determinants of health and health inequity, but even more to address the value of health in policy making process “personal versus political responsibility in health”.

The World Health Organization, Office for Europe, with its mandate to act as the strongest health advocate has helped us in that battle stating that “Human rights can help to provide an approach for redefining the ways in which governments and the international community as a whole are accountable for what is done and not done about the health of the people” (especially in Croatia where the State Constitution translates the right to health into the right to health service provision).

The new (very helpful) tool, WHO Health 2020, the European policy framework is supporting action across government and society for health and well-being. It brings a set of shared goals “significantly improve the health and wellbeing of populations, reduce health inequalities, strengthen public health and ensure people-centered health systems that are universal, equitable, sustainable and of high quality.” We strongly advocate it as a value base for macro allocation of the resources for health.

### **The moral philosophy of genetic counseling: principles, virtues and utility reconsidered**

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The moral philosophy of medicine defines the ends of medicine and how it should be practiced; it encompasses medical ethics and bioethics that address the moral issues which have special salience in healthcare and biotechnology. The moral philosophy of medicine may be based on: prima facie principles (non-maleficence, beneficence, autonomy, and justice), virtues (fidelity, compassion, phronesis, justice, fortitude, temperance, integrity, self-effacement) or on utility. Virtue ethics applied to medicine includes caring experience and puts stress on responsibility in the relationship between the doctor and his or her patient. The patient-doctor relationship can be understood in different ways, as: the doctor-centered paternalistic model; the patient-centered; consumer or a negotiated contract model; the end-oriented beneficence model.

In the paper I will discuss the differences between the principle-based, the virtue-based and the utility-based approach in the context of genetic counseling. I will consider the possibility of a unified view of these approaches which could capture the best of each of them.

The main goals of genetic counseling are: (1) providing useful information (to deliver genetic information to the parents to help them make reproductive choices; to help them understand and personalize technical and probabilistic genetic information; to elucidate the consequences of their choice based on genetic information); (2) providing medical help (enhancing parental ability to adopt to the consequences of their choice, including information about medical help and treatment); (3) providing education (exploring the meaning of the information in the light of personal values and beliefs of the parents; promoting parental preferences and self-determination in exercising reproductive choice); (4) providing psychological assistance (helping to minimize psychological distress and to increase personal control of the parents); (5) providing assistance to the prospective parents in coping with the genetic dilemma which may occur if the values on which their decision is made are in conflict.

Genetic counseling is based on such principles as: non-directiveness (promoting reproductive autonomy); beneficence and non-maleficence; confidentiality and protecting privacy; veracity and truth-telling. One may pose the question of whether meeting the afore-mentioned goals of genetic counseling does not come into conflict with the principle of non-directiveness. I claim that accommodating insights from virtue ethics and taking the consequences seriously would significantly enhance genetic counseling.

### **What is the moral universe of the Muslim researcher? – Literature and Guideline Review**

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**Context:** The field of global health research ethics faces the continuing challenge of its application within ethnographically diverse settings. Bioethics has increasingly developed a global consciousness yet universal principles to successfully guide ethical decision-making irrespective of cultural or religious contexts are not available and may never be established. Despite the variety of work that has been accomplished thus far, many researchers fail to take into consideration the pertinence of religious pluralism, cultural differences and moral diversity, which pervades in different societies. It is therefore necessary to assess existing research protocols to establish whether they allow for the necessary cultural diversity and therefore enhance applicability. Bioethical principles, from which research is conducted within a particular setting, should ideally be derived from the moral traditions of the local cultures and religions.

**Objectives:** Islam forms the second largest religious affiliation across the world and very little study has been done to explore its role in the context of research ethics. Currently there are 1.57 billion Muslims across the globe accounting for just under a quarter of the world's population. The majority of Muslims live in the developing world and therefore can form a significant cohort for research as well as those who carry out the research. Islam has generally encouraged the use of science, medicine and biotechnology as solutions to human suffering and as such it would be useful to assess its influence on local (regional and national) ethical decision-making.

**Methodology:** This paper reviews published literature, regional, national and international guidelines assessing the underlying normative principles that govern and inform ethical decision making, within the Muslim world, and compares these with global ethical principles. This piece of research is an analysis of the current research protocols submitted within the OIC (Organisation of Islamic Cooperation) and focuses on establishing the role, if any, that the Islamic tradition plays within the local and international discourse on research ethics, in informing the ethical decision-making.

**Results and Discussion:** Themes that are analysed include the complexity of the consent process involving married and single Muslim women and the consent of minors. There is also an exploration of the religio-ethical challenges raised by global pandemics such as HIV and scholarly deliberations surrounding emerging medical technologies within genetics and reproduction.

### **Ill-health retirement pensions: legitimising permanent disability?**

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In the UK, large public pension schemes offer early retirement on health grounds, or “ill-health retirement” (IHR) if the scheme member becomes “permanently incapable of work through reasons of ill-health or disability”. Occupational physicians (OPs) are the doctors who either *advise* the employer and pension scheme (Local Government Pension Fund) or *decide* (Police Pension Fund) that the applicant is indeed permanently unfit for work. This raises several ethical issues that this paper will explore. Firstly, it will be argued that in this role, the doctor-patient relationship is not a fiduciary one<sup>1</sup>, and an ethical approach that fails to recognise this (such as by the GMC) is confusing. Secondly, the medicalisation of this process will be discussed in the light of more difficult “medical” conditions. In particular, the example of applicants with “medically unexplained symptoms” (MUS) such as chronic fatigue syndrome (CFS) will be considered. Ultimately, it will be argued that fairness should be aimed for, not only for those with “disabling” conditions, but also for all scheme members.

<sup>1</sup> Tamin J. Models of occupational medicine practice: an approach to understanding moral conflict in “dual obligation” doctors. *Medicine, Health Care and Philosophy*, 2013; **16**:3, 499-506.

### **Acts and thoughts of medical students about discriminative approaches to people live with hiv pilot study**

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**Introduction:** Since HIV started to spread in 1980s homosexuals, sex workers and intravenous drug users have been seen as a source of this epidemics. That’s why these people/groups and people who live with HIV have faced discrimination and stigma. Since HIV started to spread private life(privacy), job secrecy, compulsory tests, regular tests, reproduction rights, refusal of patient by healthcare workers, refusal of healthcare worker by patient etc. started to be a part of ethical discussions of healthcare workers. Behaviours due to their professional ethics will help people who

live with HIV to reach human based healthcare services. In this context, defeminisation about the cause of stigma and discriminative behaviours are important steps to prevent stigma and discrimination. In this research we aimed to understand the student way of acting and thinking about discriminative practices and the causes of this acts and thoughts.

**Tool & technique:** This research has been implemented on medical students who study in a medical facility which has more than 1000, in Turkey, between November and February. Study has been approved by ethical committee. Data has been gathered from 319 student who wants to participate. As data gathering technique a questionnaire, which includes personal information, knowledge level forms about HIV and a section about behaviours to people who live with HIV, has been used. This questionnaire has been filled by participants. SPSS program was used for data analysis. When evaluating data, it has been looked for density distribution of topics, for analysis of permanent data between groups t-test and for analysis of categorical data chi-square test have been used. Meaningfulness of the results have been taken as 0,05 level.

**Findings:** Participants who joined are 56% female and 44% male. 48% of students are at preclinical and 52% are at clinical education. For the questions which was used to measure the knowledge level, more than 95% of the students know that HIV spreads with blood transfusion and sharing syringes. But only slightly more than half of students know that HIV can not spread with mosquito or insect bites, 40% thinks that that HIV might spread with swimming pools and 30% thinks that HIV might spread by toilet seats. Questions about behaviours and thoughts have been analysed under 4 subheadings: discrimination in treatment, tests, announcements and interactions. About discrimination in announcement, to give the information to patients partner has been approved by 55%, it's 20% for giving information to his/her family and job and it's 40% for patient which he/she has been treated with. If a person who live with HIV is a healthcare worker his/her information should give to his/her place of work is approved nearly by 60%. Also nearly 35% of participants approves that there should be signs on beds of HIV patients in hospitals which shows that this patient has HIV. Under discrimination in interaction subheading, more than 20% of participants approved rejection of HIV positive patient by doctor and nearly 35% of participants approved that HIV positive patients should be treated in a different ward. About discrimination in tests, more than 70% of participants approved that people might be forced to make HIV tests before marriage or surgical procedures.

**Discussion and results:** Participants thoughts about HIV positive patients should be treated in different wards, discriminative signs should put to their beds, they can be rejected by doctors and people might be forced to tests may be because of will of self defence but there isn't any definite results. However, students situation about being educated or non-educated about HIV, having or not having any HIV positive relative, friend or an acquaintance and being in clinical or preclinical education meaningfully affected their perceptions about discriminative behaviours. Regarding to this, it's important to take into a consideration of students being in preclinical or clinical education, for educations about creating a sensitivity for discrimination and stigma to people live with HIV. Also rearranging the questionnaire section for acts and thoughts, to understand the causes of this acts and thoughts helps the aim of this research, decreasing or even ending the discriminative behaviours and stigma.

## **Vulnerability, disasters, and human rights**

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The concept of vulnerability has been introduced in the bioethical debate rather recently. In philosophy, vulnerability has been a core notion particularly in Continental schools. In a sense every human being is vulnerable (although different expressions have been used to qualify the human predicament). In bioethics the concept has been introduced initially in the context of clinical research to demarcate groups of individuals or populations as 'vulnerable' and therefore entitled to special protections. With the globalization of bioethics, suffering and risk in the face of medical research, technologies and care have become global realities, so that the concept of vulnerability has emerged as one of the principles of global bioethics, for example in the UNESCO Declaration on Bioethics and Human Rights. The principle of respect for human vulnerability as a general statement will be endorsed by many but is it far less clear how it can be applied in various practices. The principle of vulnerability is especially salient in the context of global disasters. It points the ethical discourse in specific directions that focus more on ameliorating the conditions that produce vulnerability, rather than on emergency ethics focused on saving lives. In this connection, the human rights discourse might be helpful to focus attention and actions on structural violence, economic injustice and global solidarity. However, this requires a critical reformulation of human rights discourse, since it often adopts a neoliberal approach. It assumes that globalization offers opportunities to strengthen human security and provide basic needs, rather than threatening it. In practice, human rights discourse is no longer used to protect the vulnerable but to legitimize the global practices of neoliberalism. It often shares the vision of progress, growth and development that underlies neoliberal approaches and policies, hardly questioning the negative relationships between trade and human flourishing. Global bioethics, if taken seriously, can redirect human rights discourse to ways to prevent future disasters.

## **Behavior change or empowerment: On the goals of health promotion**

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One important ethical issue for health promotion (and public health) interventions is to determine what the instrumental goals for such practices should be. Without a clear conception of the goal(s) to be achieved, the concrete strategies of health promotion interventions, including what means to use, will be unclear or misguided.

This paper aims to clarify what (some of) those goals ought to be. It compares and evaluates two approaches to health-promotion goals, viz., behavior change and empowerment. The first model has as its instrumental goal to change people's health-related behavior in a positive direction, whereas the second approach aims at improving people's control over the determinants of their 'good life' and health.

Starting with behavior change (as an instrumental goal), the investigation shows that this approach has several moral problems. 1) It is overly paternalistic and disregards the individual's or group's own perception of what is important – something that also increases the risk of failed interventions. 2) It risks leading to 'victim blaming' and stigmatization, since it focuses on individuals (and 'risk groups') rather than environmental factors. 3) It risks increasing inequalities in health, since those who are

most in need of changes are the least likely to gain from these kinds of interventions, and 4) it centers on the ‘wrong’ problems, i.e., behavior instead of the determinants (‘causes of the causes’).

The paper thereafter argues that the empowerment approach does not have those problems. It is not paternalistic in any problematic way, since it respects the autonomous choices of those involved; it does not lead to victim blaming or stigmatization, since is not taken for granted what the problem to be solved is; it does not risk increasing inequalities, since those targeted are those in most need of change; and it centers on more fundamental problems, i.e. controlling the determinants of one’s health, not just on health-related behavior.

Finally, some specific problems for the empowerment approach are discussed and resolved, viz., 1) the idea that empowering some groups might entail disempowering others, 2) the objection that empowering people is time-consuming and costly, and 3) the fact that empowered people might choose to live lives that risk reducing their health.

### **A Scientific and Socioeconomic Review of Betel Nut Use in Taiwan with Bioethical Reflections**

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This paper will address the ethics of betel nut use in Taiwan. It first presents scientific facts about the betel quid and its consumption and the generally accepted negative health consequences associated with its use. A visitor to Taiwan may be surprised by the abundance of betel nut stands all over the country, often advertised with neon signs and scantily clad young women. The deleterious health effects of the betel nut are well documented. Taiwan has the highest incidence of oral cancer in the world. From 2001 to 2012, the incidence of oral cancer increased by 20.7%. Esophageal cancer was the sixth leading cause of cancer death among men in Taiwan in 2003. Coronary Artery Disease (CAD) is the second leading cause of death after cancer, which accounted for 10.8% of all deaths in Taiwan in 2010. All these can be traced to the chewing of betel nut, which is currently one of the most widely used uncontrolled addictive substances around the world, with 10 to 20% of the global population consuming it. In fact, with regard to the worldwide popularity of central nervous stimulants, the betel nut ranks fourth after nicotine, alcohol, and caffeine. Given the dire health tolls of this nut on the population, it is surprising to note a lack of bioethical literature on this issue. A cursory search on the database of the Kennedy Institute of Ethics did not yield a single result when the words “betel nut” were entered. The paper will also look at the social, economic and cultural factors contributing to its popularity in Asia. The governmental and institutional attempts to curb betel nut cultivation, distribution, and sales will also be described. Finally, the paper will analyze the bioethical implications of this often ignored subject from various perspectives: human dignity in the face of cultural diversity, health as a fundamental good and its tension with local cultural practices, the need to protect vulnerable populations, the need to provide informed consent for decision making, and behavioral ethics in institutional and organizational responses to the problem.

## **The ethics of smokefree policies for outdoor public places**

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**Background:** Smoking outdoors can result in harms to others, through secondhand smoke, the normalisation of smoking, the modeling of smoking behavior to youth, and through cues to smoke for those trying to quit or stay quit. Smokefree outdoor places policies (SOPs) reduce such harms.

There are a range of ethical concerns about SOPs, including discrimination against vulnerable groups, stigmatisation, and possible increased smoking in indoor private places. A number of writers have written about ethical aspects of smoking denormalisation, notably Courtwright, but fewer on the ethics of SOPs.

**Aim:** To examine the ethical issues of smokefree policies for outdoor public places.

**Methods:** Relevant evidence on the possible harms of SOPs was gathered and examined, in particular on:

- Any increased private indoor smoking.
- Whether SOPs stigmatise smoking and/or people who smoke.
- Any impact on broader social or economic inequities.
- The analysis was underpinned by consequentialist and human rights values, along with public health ethical frameworks such as by Kass. The definition of stigma used is given by Stuber et al 2008, for whom stigma is the ‘negative labels, pejorative assessments, social distancing and discrimination that can occur when individuals who lack power deviate from group norms.’

**Results:** There is strong evidence that smokefree *indoor* public policies decrease *private indoor* smoking, but the effects of SOPs on private smoking need to be investigated. Evidence of the perceptions and fears of stigma by smokers as a result of SOPs was qualitative, and the analysis of the evidence in the literature raised questions. The questions include the degree to which the analyses sufficiently recognised (i) the ambivalence about smoking by many smokers, and (ii) the wish of most smokers to quit, and to have environmental constraints such as SOPs to help them quit.

The evidence of any resulting inequities (eg, disproportionate impacts on poorer people) was mixed. Comprehensive smokefree policies (which include SOPs) are likely to have more benefits than harms for such groups. There is evidence that SOPs reduce the normalisation of smoking and exposure to secondhand smoke, reduce cues to smokers and those trying to quit, increase successful quitting, and reduce modeling to youth.

The analysis indicated that the possible social isolation for smokers may be relatively temporary. As soon as smokers cease smoking, smokefree area policies do not restrict them, or mark them (except possibly by self-stigmatisation). If smoking in an outdoor smokefree area is generally regarded by a population with great disapproval or as disgraceful, then that *activity* may be stigmatised. Some smokers agree that there is a link between reducing smoking visibility, and reducing smoking prevalence.

**Conclusions:** There is a need to disentangle the discouragement of the activity of smoking by smokefree policies, from attitudes to people who smoke. SOPs can be ethically justified if they can help curtail the tobacco epidemic and its associated impact on health inequalities (often felt by low-income populations and ethnic groups). However, the health sector needs to remain aware of possible consequences

such as stigmatisation, and implement and enforce SOPs in ways that minimise such risks.

### **The ethics of tobacco tax revenue: the case for dedicating tobacco tax revenue to tobacco control**

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**Background:** Tobacco use is addictive, and a cause of health loss and inequalities. Because of government failure, few potential users fully comprehend or apply to themselves the consequences of starting use. Thus largely involuntary tobacco purchases can contribute to poverty.

Tobacco taxation is effective in reducing youth becoming addicted to tobacco, and in increasing quitting. In reducing addiction, such taxes increase autonomy for the individuals. Tobacco tax increases may reduce health and social inequalities, as poorer people tend to be more price sensitive and are more likely to quit or reduce consumption.

Tobacco taxation may also result in inequity. Tobacco taxation is generally regressive, as poorer people spend a greater proportion of their income on tobacco than those richer. Also, in many countries, a greater proportion of poorer people use tobacco than richer people. For those unable to quit, tobacco tax increases can increase household poverty. Can this be ethically justified by the use to which tobacco tax revenue is put?

There is little published research specifically on the ethics of the use of tobacco tax revenue, eg Goodin (1989), Bitton & Eyal (2011).

**Aim:** To examine the ethical issues of the use of tobacco tax revenue, and possible solutions.

**Method:** Relevant data on tobacco taxation and tobacco tax revenue use from a range of countries was identified. Ethical analysis of using tobacco taxation for general government purposes was undertaken with reference to Nancy Kass's public health ethics framework, as well as public health values including equity of outcomes, concern for the vulnerable, and reciprocity (in this case, the duty that states have to redress harms from their actions).

**Results:** There is a general imbalance between tobacco tax revenue and spending on tobacco control. For instance, in the United States between 1998 and 2010, tobacco control spending was only around 3% of tobacco tax revenue. A small minority of jurisdictions nominally dedicate some tobacco tax revenue to tobacco control, this is nowhere is sufficient to quickly reduce tobacco use (eg, to under 1% prevalence within ten years).

Thus governments widely use a dangerous product to raise tax revenue from addicted users for general purposes, often from disadvantaged populations. This revenue is not adequately used to reduce tobacco use, generating avoidable harm and injustice such as disproportionate tax burdens. The harms can be minimised by:

- The use of some of the tobacco tax revenue for tobacco control programmes, sufficient to quickly reduce tobacco use prevalence.
- Also using *non-tax* means to reach a desired tobacco use goal. A strong comprehensive tobacco control programme could quickly reduce tobacco tax revenue, and thus the ethical concerns with its use.

- As well as using options 1 and 2, the disadvantages generated by regressive tobacco taxation would be addressed by ensuring that overall government taxation and spending packages reduce health and social inequity

**Conclusions:** The ethical issues raised by use of tobacco tax revenue can be addressed with appropriate funding and strengthening of tobacco control programmes, and by making the overall taxation and welfare system more equitable.

### **The experience of Croatian Red Cross in Vinkovci area with the disaster situations**

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Croatian Red Cross is integral part of the protection and rescue system of the Republic of Croatia. Representatives of the Croatian Red Cross are members of crises management bodies on national, county and city level. Croatian Red Cross participates in all the activities linked to crises, during all phases – from preparedness activities to response and recovery phase.

Croatian Red Cross implements preparedness activities and responds in case of disasters and other emergencies. It prepares disaster response units on local and national level and informs citizens of all ages about correct procedures and behaviour in emergencies. Disaster preparedness activities include trainings for disaster response units that are organized on the city and county level. Every member adopts basic knowledge in first aid, psychosocial support, security and self-protection and communication. After initial education, they can specialize in one of the areas: first aid (advanced training), assessment, tracing, shelter, water and sanitation.

This presentation will give an overview of the activities in the area of disaster preparedness of Croatian Red Cross branch in Vinkovci. Vinkovci is a town near the border of Croatia and Serbia and from 1990-ties Red Cross in this region took part in disasters response. It was involved during the Croatian War of Independence in providing for internal displaced persons, refugees from the conflict area since it was near Vukovar region. In the May of 2014 a dam in a nearby region in Gunja broke and the nearby area was flooded. Again the Red Cross of Vinkovci was involved in disaster response. Finally in the autumn of 2015 the crisis in Syria resulted in flood of refugees on the Balkan route. Again the area of Vinkovci near Croatian Serbian border was faced with a challenge of management of huge number of refugees that were in transit through Croatian territory.

### **Does alleged impaired self-control make individuals addicted to heroin vulnerable research subjects in heroin-related research?**

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Heroin addiction, and addiction in general, remains a challenge to medical research and health care in terms of effective treatment – what works for one does not do so for another and some, it seems, are beyond help. More research on heroin use and addiction are thus called for. However, it is generally acknowledged that heroin addicts are a vulnerable research group. Analyses of heroin-addicted individuals and informed consent in this context have been an object of debate in several articles from

the beginning of the millennium (e.g. Charland 2002). Informed consent requires the agent not only to be competent but also give it voluntarily. This has been questioned because of alleged features of heroin addiction. Until recently the discussion has focused on heroin-addicted individuals' desires for heroin, whether these are irresistible and thus pose a problem for giving consent. Still, in light of empirical evidence, there seems to be a consensus more or less that the problem is not whether the addicts can resist their desire for heroin (e.g. Uusitalo & Broers 2015). At the same time, it is nevertheless generally agreed that addiction involves impaired self-control (e.g. Levy 2013). If the problem is not the strong, compulsive desire that impairs the agent's control over, for instance, consenting to a research in which heroin is prescribed for the subjects, what is this impaired self-control and does it contribute to the view that heroin-addicted individuals are indeed vulnerable research subjects in heroin-related research.

In this paper, I will first consider, in light of current empirical evidence on heroin addiction and its treatment, how the notion of (impaired) self-control should be understood in this context and analyse whether it relates to the vulnerability that has been taken at face value in addiction-related research. This kind of philosophical analysis is needed for medical research to carry out studies on improving outcomes in addiction treatment in an ethical way.

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### **When economic neoliberalism is changing healthcare and its core values**

#### **A Belgian perspective**

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In this paper I argue that because of the evaporating of 'les grandes histoires' or 'ideologies' there is not enough resistance anymore against economic neoliberalism, which has become de facto the overarching worldview in most parts of the world. The neoliberal project is to turn the "nation-state" into a "market-state," one with the primary agenda of facilitating global capital accumulation unburdened from any legal regulations aimed at assuring welfare of citizens.

In theory each country wants to provide excellent health care for its citizens. However, since a few years the healthcare systems in welfare states have come under pressure.

In order to make these position statements concrete I will use examples how a not-for-profit large general hospital in Belgium deals with an economic neoliberal government policy. E.g. every hospital has to have an integrated electronic patient record or database by 2018. As the hospitals themselves cannot afford to pay for these expensive systems they are obliged to negotiate with the physicians to contribute. As a consequence the fees of these physicians rise. E.g. in order to avoid a deficit step by step patients are charged more for out of pocket services (water, internet, television,

Wi-Fi, refrigerator). At this moment, in Belgium about 25% to 30% of healthcare costs are out of pocket which means that people with a low income regularly avoid doctor visits and are terrified when being hospitalized because of the financial consequences when they do not have private insurance. At the same time it is remarkable that businesses who feed on the healthcare system are being spared by this economic neoliberal policy (pharmaceutical companies, software companies, consultant agencies) because they provide jobs, pay taxes.

In this paper I argue that healthcare has indeed an economic component but the foundation of health care is in essence ethical. A lot of what is being done in 'cure and care' has no benefit/profit if you look upon it from a market point of view. This type of 'cure and care' is only justifiable if one agrees that 'cure and care' is about certain values. As a society we invest a lot in old, very old people, patients in a coma, mentally retarded, persons with severe psychiatric diseases, terminally ill patients. Economically unprofitable but as a society we once thought that this is the way it should be. This conviction is a purely ethical one. Therefore I make a plea to give healthcare its ethical foundation back. Healthcare is not something that should be regarded as a commodity that one can buy if one has the budget for it. Healthcare should be regarded as a right. Economics plays a role but it should not be a determining one. Especially politicians should be aware that healthcare is another type of 'economics' than the one on the market. Therefore we need to find a new ethical consensus concerning the core values of healthcare and profit cannot be one of them. Perhaps it suffices to remember why our predecessors wanted to build a healthcare system with universal access.

### **"Yo soy yo y mi circunstancia": the role of social capital in the explanation of health inequity.**

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The importance of the broad social context on health and health behavior is largely acknowledged in empirical research. More specifically, a true 'explosion' of interest for the concept 'social capital' has been observed in public health literature since the mid of the 1990's (Kawachi, Subramanian, & Kim, 2008). Social capital broadly refers to the idea that social networks are potential resources for individuals, communities, and the society as a whole (Morrens, 2008).

While the general association between social capital and different health outcomes is widely studied, less attention has been given to the question whether social capital plays a role in health inequity, is the relationship between social capital on the one hand and health outcomes on the other hand is comparable for people with a differing socioeconomic status (SES)?

We used data from a cross-sectional study in Ghent (Belgium) to explore social capital's interaction with socioeconomic status in relationship with smoking. Social capital was measured both at the individual and neighbourhood level. In most cases, the association between indicators of social capital and smoking were not contingent upon socioeconomic factors. However, some significant interactions between social capital and SES were detected, amongst others for individual generalized trust, neighbourhood social support and neighbourhood informal social capital. Remarkably, in these cases, high levels of social capital seemed to be associated with higher smoking rates for those living in a vulnerable socioeconomic

position, but with lower smoking rates for individuals with a better socioeconomic position.

Combining these results with the observations that there is a clear social gradient in smoking rates (with higher smoking rates associated with low SES), our results illustrate that the way in which people are embedded in social networks is essential to fully grasp the manner in which they make health related choices. While it is clear that health behaviours are partially based on voluntary individual choices, it seems that aspects of one's social position and the social context determine the choices people are able to make since they determine the availability and social acceptability of different potential behaviours and as such influence individuals' health (Bourdieu, 1984; Frohlich et al., 2001; Cockerham, 2005). As such, our results are in line with literature that describe the limited health effects of policy measures and health campaigns that address health damaging behaviour within a framework of individualist behaviourism by placing people's individual responsibility central (e.g. anti-smoking campaigns that address smoking rates via health education on the health risks of smoking) (Szreter & Woolcock, 2004; Cockerham, 2005).

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### **Public Health Ethics and the Social Determinants of Health: Healthful Environments as Meta Public Goods**

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An inhabitable environment, free from toxic pollutants and the worst effects of climate change, is typically seen as an archetypal public good, the substance of a human right, and an important social determinant of health. It is non-excludable and jointly produced, and is necessary for the promotion and protection of individual welfare. Correlatively, environments in which exogenous health threats, such as disease pathogens and environmental hazards, are controlled also qualify as public goods, in that they can only be produced, enjoyed, and maintained collectively. Further, such environments are of fundamental importance for the promotion of individual and public health, while access to them is heavily socially determined.

However, the demands of delivering and preserving such 'healthful environments' can sometimes appear to conflict with adequately respecting individual rights to finite resources and important personal freedoms – undermining the concept of rights to such goods by rendering the guarantees they entail contingent rather than absolute. Conversely however, excessive deference to individual entitlements can endanger public health generally, by weakening health promoting infrastructures. For example,

pharmaceutical policy intended to impede the evolution of antimicrobial resistance may restrict the availability of certain drugs in order to preserve the efficacy of important medicines. While imposing such restrictions may lead to increases in mortality and morbidity from otherwise treatable diseases in the short to medium term, failure to do so risks exposing large numbers of people to significant risk of major harm in the long term.

In this paper, I argue that thinking about public and individual health in terms of a generalised welfare-promoting public good, rather than entitlements to specific goods or services, enables us to reason effectively about theoretical questions about the nature and extent of individual rights and duties, and the preservation of public health. I argue that acknowledging a 'healthful environment' as a Meta public good in this way provides a highly effective way of reasoning about both (domestic and global) public health policy, and individual rights and wellbeing. In addition, I argue that thinking about the right to health care in terms of access to healthful environments provides a valuable, and novel, way to resolve tensions that exist between competing rights claims – particularly in contexts where important personal freedoms might be thought to be restricted by the demands of public health and the entitlements of other persons. In doing so, I also suggest a novel approach to resolving inequities in the accessibility of important social determinants of health.

While the importance of health public goods is increasingly acknowledged in the literature, my paper will offer an original suggestion of how this importance might be used to create just, effective public health policy. I will show how conceptualising healthful environments as Meta public goods can provide the heuristic and analytical tools with which to assess the just extent of our entitlements to finite resources, while simultaneously offering a framework upon which to construct just public health policy.

### **“Permissible Inequalities” and Right to Health in Egalitarian Concerns for Inner-Urban Poverty: A Case Study of ‘Cage People’ in Hong Kong**

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What are the moral obligations of the state for the well-being of the inner-urban poor? How can justice as fairness – greater equality of welfare, resources, and capability – be achieved for the population beyond provision of the primary goods such as healthcare? These ethical questions are rooted in my participatory ethnography of ‘cage’ dwellers in Hong Kong (HK).<sup>1</sup>

Hong Kong’s Gini coefficient, a measure of income inequality, is 0.537, the highest in developed countries. One of the unique features of the deprived communities is ‘cage-dwelling’. A cage is usually described as a tiny cubicle with walls made of steel wire mesh and a floor of wooden planks. The area of the floor measures 20 square feet. Usually, 12-18 cages are piled on top of each other in an area measuring 650-700 square feet. ‘Cage’ first appeared in the 1950s as a result of the influx of refugees from mainland China. Since then, the situation has gotten worse with the number of cage dwellers now estimated to be about 200,000.

Cage dwellings are located in historically under-developed, heavily populated, decaying urban areas, representing inner-city slum, informal, overcrowded settlements lacking adequate security, sanitation, protection and other infrastructure. The dwellers are disproportionately at increased risk of developing health problems

caused by social disorganization. The solution to these problems requires a normative paradigm to identify the social-aetiology of problems and effective interventions by answering this question: How a theory of justice governing social institutions should respond to ‘cage dwelling’?

While the elimination of unequal distribution of primary goods is impossible, the right to health should be advocated as a minimum standard of human quality living. If justice is merely focused on the distribution of primary goods, it might result in “permissible inequalities” with the following logic: *“There is nothing else we could do. Their living condition is misfortune but not unfair because primary goods are already provided for everyone (e.g., access to healthcare (‘right to health’), public utility, opportunity for public housing<sup>2</sup>).*

The moral concern here is cage-dwellers’ lack of power to convert the primary goods into well-being with equal efficiency. The emphasis should not be made on goods – primary or not – but on what people, given their variability, can do and be with those goods. This capability suggests that the primary goods in welfare and resource-based justice are wrong indicators, and provides further justification for moral obligation for the care of the cage-dwellers. Justice is to be judged by the fairness of the relationship between goods and the people, and impairments of enhancing their capabilities over the course of their whole lives.

<sup>1</sup> The ethnographic study is funded the University Research Grant Council in Hong Kong. For information about “cage people” please see the following articles:

<http://edition.cnn.com/2009/WORLD/asiapcf/10/28/cage.homes/>

<http://www.dailymail.co.uk/news/article-2275206/Hong-Kongs-metal-cage-homes-How-tens-thousands-live-6ft-2ft-rabbit-hutches.html>

<http://www.scmp.com/news/hong-kong/article/1444585/plight-hong-kongs-cage-home-dwellers-worse-now-25-years-ago>

<sup>2</sup> The government built up public housing apartments for ‘cage’ dwellers but they were located far away from city where economic opportunity is lacking. They are dependent upon inner-city economic involvement, like daily-wage work. Public housing opportunity without economic opportunity is ineffective, problematic, and unethical.

## **Who gets to decide when we are gone? - On limitations of proxy decision makers in transplantations**

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Increasing pressure on global scale requires us to procure more transplantation organs and tissues for the ever-increasing number of patients who urgently need organ replacements and other procedures involving human tissues. The existing shortage is an ever more important factor for the societal disease burden in the developed countries. This situation puts medical professionals in a position where they have both moral and professional obligation to obtain such organs or tissues. Depending on donation system in a particular jurisdiction consent maybe be available from proxy decision maker to procure tissues or organs of dead or dying (in some cases just incapacitated) patients for the benefit of others, or it may be only a family’s objection that even if not legally binding might be an ethical issue. When proxy decision is required a family member, a lawyer, a judge must make the decision. He or she has to take into account various laws that may regulate the situation, but also the ethical aspect of the situation. Weighing the various normative concerns he or she should arrive at a decision. That is the ideal. In an actual situation the proxy decision maker

is an acting human agent with all limitations characteristic of any person making decisions about his or her own body. There are cognitive biases involved, mental disturbances, trauma, limited intellectual capabilities, various ideological backgrounds and many other factors that will influence this process.

The purpose of my presentation is to provide an outline of limitations of decision makers in tissue or organ donation processes and their various types: the ones resulting from simply being human, from mental strain, from pathological processes of mind and body, limited bodily function etc., but also from normative limitations as expressed in ethical principles such as *best interests*, *beneficence* and *justice*. The obvious and most common example of obstacles to proxy consent in jurisdictions with opt-in donation system will be the ability of proxy decision makers to conceptualise and accept the notion of brain death and its implications that is far less obvious than some bioethicists would like. The resulting framework will show which types of decisions are even possible to conceptualise as autonomous and which are possibly beyond the capacities of at least some agents.

This presentation is a part of a project to create new standard of competence assessment and here I would like to show how it extends to healthy subjects who act as proxies. It also aims at showing the ethical boundaries and limitations of proxy decision making in general, that among other things is based on incomplete and biased knowledge and biased thinking.

## **Reflections of Program Creators and Practitioners on Parental Education and Informed Consent for Expanded NBS in Israel**

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**Background:** This study explores views of officials and physicians regarding parental education and informed consent for newborn screening (NBS) in the recently expanded program in Israel.

**Methods:** Fourteen in-depth interviews with program creators and other practitioners involved in the various stages of decision-making, design, implementation, and delivery of NBS and six interviews with informants providing context and background were conducted and analyzed qualitatively.

**Results:** 1. Program creators, who were involved in the creation, design, implementation, and delivery of the expanded NBS program ("program creators"), as opposed to practitioners who were involved only in the delivery ("practitioners"), emphasized the "indifferent" attitude of parents of newborns to NBS 2. Program creators advocated higher and more ethical standards for NBS education and informed consent than do practitioners.

**Discussion:** Practitioners, because they were less involved with and less committed to the program, did not focus on the indifference of parents. Moreover, program creators were concerned with the lacking NBS education and insufficient opt-out mechanism while practitioners were skeptical about the ability to achieve genuine informed consent and were concerned about their added workload if higher and more ethical standards of education and informed consent are implemented. Consequently, program creators, much more than practitioners, supported higher standards of education and consent for NBS.

**Conclusion:** In order to ensure adequate and ethical operation of NBS programs, in particular education and consent mechanisms, it is recommended that prior to its

expansion, an expanded forum of practitioners be involved in decision-making regarding informed consent for screening and education.

### **Viral Threats and the Anthropocene**

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According to David Quammen (Spillover 2012), “zoonotic spillover” (viral migration from animal hosts to humans) is “a word of the future, destined for heavy use in the twenty-first century”, representing “the most significant growing threat to global health”. The threat of emerging human and animal viruses can be attributed to a combination of factors: globalized travel and trade; increased urbanization and exponential population growth; climate change; environmental and ecosystem disruption; changing social and economic conditions, and pathogen adaptation. At the same time, living in the terabyte age, we are facing an explosion of health data, also concerning viral threats. Rapid sequencing techniques provide huge amounts of data concerning potential pandemics, more than we were looking for or are able to process. Instead of scarcity of information, we are confronted with information overload, blurring of boundaries between healthy citizens and patients. And yet, we continue to produce more data, notably enabling early detection. In my paper I will address the moral dimension of these issue from an oblique perspective, especially paying attention to the way techno-scientific, societal and normative responses to viral threats are enacted in genres of the imagination (such as movies and novels). Three normative responses will be assessed: (a) viral threats are presented as punishment for our irresponsible and unsustainable behaviour; (b) this anthropocentric view is challenged by the awareness that the earth is a microbial and viral planet, out of our control by definition; but finally (c), I will argue that, as we have entered the anthropocene and the biosphere is increasingly reorganised and absorbed by the noosphere (the ‘thinking layer’ of human research and technology), the normative framing of viral threats must be revisited as well.

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