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**“WORST CASE BIOETHICS”**

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**ABSTRACTS**

**Identifying the worst case scenarios – how to conceptualize events outside of normal human experience in trauma victims following a disaster**

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The psychologically fragmented individual, suffered by the effects and consequences of a disaster, offers a particular challenge to the responding medical practitioner. How may such trauma be understood? For example, Norris et al (2002) reviewed literature on the psychosocial consequences of a (natural) disaster, concluding that over a third of studies described individuals who suffered from severe distress including diagnosable disorders.

First, an ontological distinction will be made between a trauma that occurs (in)ternal to an individual and a trauma that occurs (ex)ternal to the individual. Natural disasters are unlike other forms of trauma because the individual can suffer from the destruction of property, and the disintegration of their lifestyle and livelihood. However, in this paper, I refer to phenomenological aspects, which are apparent during a rupture of the land.

Second, the paper will lead on to discuss an individual’s psychological symptoms as part of a symbiotic relationship with their land; the Other. This allows for a re-framing of the individual’s situation as a transformative narrative rather than a pathology. In turn, the question is then begged about the applicability of a Post-Traumatic Stress Disorder diagnosis.

In the context of the ‘worst case/s of bioethics’, the examination here conforms to exploring the ethical implications of diagnosis. This is in contrast to many of the discussions that are similar in nature in the sense that they refer to the treatment of the individual in the emergency medical setting following a natural disaster. However, in the case of the traumatized individual, I argue that our first ethical consideration lays with the diagnosis,

rather than the treatment, of the individual. In order to develop this argument, this paper is strongly focused on the nature of an individual’s (psychological) distress – finally concluding that the focus on the individual’s rupture of experience will accommodate an ownership of their being-in-the-world (their territory) and an understanding of their altered narrative (their landscape) following the (named) disaster.

**Are “Undue Inducements” a Problem for Benefit Sharing?**

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When medical research is conducted in resource-poor countries, the results are often primarily for the benefit of health care systems to which the research participants have little or no access. In such cases the research participants carry the burdens of participating in the research, while patients in developed countries enjoy the benefits. To correct this injustice, various benefit sharing frameworks have been proposed. One of the main problems for benefit sharing is how to avoid the problem of undue inducements. If people in resource-poor countries are offered significant payments or health care services which they would otherwise not have access to, the fear is that they might be “unduly induced” to participate in the research. One argument against benefit sharing is that offering any significant benefits to research participants will result in undue inducement, which is prohibited by most international research ethics guidelines. In this paper I discuss the meaning of “undue inducement” and in what ways inducement may be perceived to be ethically problematic. I argue that the problem of undue inducements is insignificant and should not be used as an argument against benefit sharing frameworks.

**Hospital under Fire—Ethical Considerations**

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In 2006, Rambam Medical Center (RMC), the only tertiary care center and largest hospital in northern Israel, was subjected to continuous rocket attacks. This extreme situation posed serious ethical dilemmas, which the hospital's leadership had to address. Immediately after the Second Lebanon War started on July 12, 2006, RMC was notified of an emergency condition and took the necessary measures to prepare for a mass casualty situation. Shortly after, when missiles began falling within close proximity of the hospital (approximately 60 missiles fell within half a mile of the hospital), it became obvious that the situation was completely different from previous mass casualty events because the hospital itself, patients, staff, and visitors were under constant serious threat.

Faced with an unprecedented situation, the hospital leadership made several major decisions that determined their actions throughout the war, as follows: The hospital’s first priority would be delivery of emergency surgical and medical services to the injured from the battlefields and home front. The RMC staff already had years of experience dealing with mass casualty situations, hence, this decision seemed natural and was received with no reservations.

All elective medical and surgical services to the civilian population would still be provided. Although over a third of the civilian population had left the bombarded areas and moved to safer areas of the country, those remaining still needed medical services. This need was intensified since the war situation led to closure of many ambulatory clinics, dental clinics, pharmacies, and peripheral dialysis services. For many days, patients could receive medical services and supplies only through hospitals. This decision required working fully staffed, every day, exposing employees to danger while in, or on the roads coming to or leaving the hospital. Some of the measures taken to reduce this threat included providing underground lodging for staff and their children, and providing shrapnel proof vehicles for transportation.

Danger to patients, staff and visitors, would be reduced as much as possible. Wards facing north, and the top three floors, were evacuated to unused underground spaces and corridors. Injured soldiers and civilians were transferred to other hospitals in safer areas as soon as their conditions allowed. Unfortunately, due to the shortage of shielded spaces, not all wards and patients could be relocated to safe areas. This situation led the RMC leadership to modify construction and renovation plans which were at an advanced stage; a much larger sheltered area was added and funds were allocated for that need. A new fortified Emergency Room has since been constructed and the new underground parking lot was re-planned to serve also as a fortified emergency underground 2,000-bed hospital.

Modern warfare will continue to involve civilian population and institutes. Hospitals must be prepared to function and deliver treatment while under fire and other threats. Many functional and ethical dilemmas arise in these situations, dilemmas that should be recognized, researched, and explored in advance.

**Extreme side effects and emergencies: The principle of the double effect (PDE) meets human rights.**

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The principle of double effect has developed in Catholic moral theology and won acceptance in traditional medical ethics as an instrument for dealing with difficult moral dilemmas such. However, some key conceptual problems within the PDE have remained controversial. Two key questions are whether the PDE is applicable when the minor effect is inevitable, and whether it is applicable when the minor effect violates what we would refer today as |an extreme side effect" or a violation of a human right (e.g. the effect is a loss of life).

In this presentation I will recreate the PDE, incorporating in it contextualization as well as the requirements of informed consent, Michael Walzer's notion of "double intention". Reformulated thus I will examine the applicability of the PDE to dilemmas of severe side effects, military medicine and major public health initiatives. The presentation is based on a section from a new book, "Human dignity, human rights and responsibility: the new language of bioethics and bio-law" by MIT Press.

**Non Battlefield Military Medical Ethics in Israel - the perspective of responsibility**

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While battlefield emergency medicine has its own ethical issues and dilemmas (regarding soldiers of both sides of the conflicts and local population as well), the ethics of routine peacetime military medicine involves its own special set of problems.

In our research we studied military documents and conducted interviews with military physicians in order to reconstruct the moral ethos and values of Israel's medical corps.

Israel's armed forces and public medicine have evolved together during the mid 20th century with the construction of the Zionist national entity eventually becoming the sovereign state of Israel. This has embedded social and community values and morality in the professional ethos of the IDF's (Israeli army) medical corps. While non-obligatory professional western armies around the world define the medical corps' chief role in terms of preservation of combat power, the professed objectives of the Israeli medical corps are more complex. The IDF consider itself "the peoples' army", thus absorbing civil values and over-spilling military values to the civil society. The symbiosis between military and civil life in Israel (which has also been a target of much criticism) does not allow the full militarization of the military medical service.

The military system is characterized as a "total institution" that creates and protects the vulnerability of its soldiers at the same time. We suggest that the moral foundation of the connection between the army and its soldiers is constructed of two core moral principles - contractarianism (as in Rawlsian model) and responsibility. Our research and thesis strives to define the boundaries of military medical responsibility based on conflicting needs and interests characterizing military medicine.

**Too severe to transmit to offspring? Reflections of mutation carriers on hereditary cancer and reproductive decision-making**

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Genetic testing used in conjunction with reproductive technology has considerably expanded the reproductive options open to persons susceptible of transmitting to their children a genetic mutation associated with a serious disorder. In the past, choice was restricted either to taking the risk of transmitting the familial disease to their offspring, or to not conceiving one’s own children and eventually adopting a child or, more recently, conceiving a child with donor gametes. Genetic testing can now be carried out on the fetus (prenatal diagnosis – PND) and even on the *in vitro* embryo (preimplantation genetics diagnosis – PGD). However, in case of a positive result, the only form of “prevention” is the termination of the pregnancy after PND and the discarding of affected embryos after PGD. Because these are morally and socially controversial solutions to the problem, many countries restrict access to PND and PGD to diseases considered as particularly serious, even though there may not always be agreement as to what or who defines a disorder as “severe”.

In the context of such debate, little attention has been given to the reproductive concerns, plans and choices of the carriers of a mutation themselves. What are their thoughts concerning the acceptability of taking the risk of transmitting a mutation to the next generation? What is their opinion concerning PND and PGD as reproductive options in such circumstances? These questions are all the more difficult to answer when the presence of a mutation is associated with an increased risk but not a certainty of developing a disease.

Drawing on the results of a study done in France that investigates the way in which carriers of a mutation associated with hereditary cancer reflect on their reproductive decisions, we would like to show how their thoughts on reproductive decision-making are modulated by their personal evaluation of the seriousness of the disease. Although carriers may refer to the medical criteria used in making such an evaluation, they do not necessarily endorse the idea that some diseases are objectively more serious than others. By comparing the responses of carriers of an early onset (retinoblastoma) and a late onset (hereditary breast and ovarian cancer) disease, we would like to show that the evaluation of the seriousness of any one disease may be variable among carriers, that the factors affecting this evaluation are related to the characteristics peculiar to each disease and their perceived impact on what carriers define as a normal family life. This will influence their decision to have or not to have children, including whether or not to take extraordinary measures to have them.

**Cosmopolitain altruism - the Cyprus case**

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Transnationally operating transplantation systems, international networks of biobanks and the altruism of donors afford a "culture of giving" that transcends national borders. Based on empirical data from an ethnographic study on practices of bone marrow transplantation in Cyprus it will be argued that we are currently witnessing an emergent cosmopolitan citizenship that implicitly or explicitly questions national biopolitical regimes.

**On medicine in political conflicts: Bone marrow transplantation to Gaza children in Israel**

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Decades of occupation and political upheavals have left Gaza healthcare system unable to provide many common procedures including life-saving ones. Seriously ill Gazans are thus referred by the Palestinian Authority to treatments abroad, often to Israel. In this paper I look at Gaza children who undergo bone marrow transplantation in Israel. Due to financial limitations, the Palestinian Authority funds only transplantations from kin donors. The transplantation thus draws a line between Israeli children to whom the world donor repository is open, and Gaza children in similar medical conditions, who are confined to their family circles. This difference, which coincides with the confinement of Gaza patients and their attendants to the hospital premise and with their continuous stay in the hospital for month long treatments, due to movement restrictions, will provide the backdrop for some ethical questions on medical treatment in a foreign country that is greatly responsible for the patients’ very need to seek therapy abroad.

**Ethical issues in providing healthcare during war, pandemics and disasters - The role of physicians in war preventive measures against terrorism: bioethical issues**

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Today, the concepts of soldier and war are changed because of the terrorism and the war on terrorism. The enemy is no longer another defined State: now he is invisible, doesn’t follow the usual rules of armed conflict and, sometimes, he doesn’t wear a uniform so that it will be always more difficult to understand where he is and what he does. In the traditional warfare, the soldiers were not responsible for their actions and they knew that if they had killed an adversary they would not be prosecuted, except that if they had committed serious crimes against humanity. Now, instead, the *other* is unpredictable, he is able to do everything also against civilians; the soldiers are no longer afraid of suffering the same fate as their enemies because they know that the *others* don’t have sophisticated weapons and a big numbers of soldiers as they have. In a context like this, it is possible to think back to introduce, another time, some practices that had been excluded from the international law after many Declarations. From the literature we can deduce that there are two different measures to be evaluated to prevent terrorism, but both generate bioethical issues. On one side, to rebalance the warfare after the acts of terrorism and to obtain information to prevent future actions like this and save lives, some States contemplate to using, as in the past, enhanced interrogation techniques as torture, but is it right that the lives of many are saved while the dignity of some is violated? And then, if those preventive measures have to be an exception how to avoid abuses? Is not likely that, in this way, also the violence more stringent will be justified? On the other side, instead, sTraduci da: italiano

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Alphaome States choose to limit the freedoms of its citizens to provide them more safety, but it is reasonable to restrict the rights of some to ensure more security to other? In Israel, for example, to protect the society against possible terrorist attacks the Palestinian ambulances (PRCS) should be controlled quickly to allow them to easily reach the hospital, but, many times, they have to wait, at the check point, an Israeli vehicle of the Magen David Adom (MDA) whereby the patients will be transferred according to the method of “back-to-back”. This causes many delays and even medical risks in certain cases. How to guarantee the protection of the lives of some, without denying the best cares to others?

**The doctrine of double effect: Resuscitating practical wisdom in palliative care ethics**

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In this paper I shall analyze how *phronesis* may be applied in the liminal context of palliative care ethics through the Doctrine of Double Effect (DDE). Aristotelian practical wisdom or *phronesis* is considered by many philosophers of medicine to provide the foundational moral framework for medical ethics. Defined as the moral and intellectual virtue that disposes one habitually to choose the right thing to do in a concrete moral situation, *phronesis* provides an approach that takes into account the variability of individual patients. Relying on *phronesis* allows medical ethicists to apply various philosophical principles to the fluid changing context without slipping into moral relativism. Similarly, one would expect that *phronesis* would provide the appropriate moral framework for palliative care ethics. For example, in their *Palliative Care Ethics: A Companion for all Specialties*, Randall and Downie argue that *phronesis* is necessary to determine the *intrinsic* and *extrinsic* aims of palliative care. However, it is questionable how best to apply *phronesis* in the context of palliative care that is characterized by liminality. The anthropological concept of liminality refers to transitional states in the human life cycle characterized by the overturning of accepted norms and values. The heightening of human contingency in liminality means that even *phronesis* might not by itself provide an adequate moral framework for palliative care ethics, evidenced most clearly in the DDE. Rooted in the Catholic natural law tradition, the DDE states that an equivocal action is morally legitimate provided that the good and not harmful effect is intended, even though the unintended harmful effect may be foreseen. DDE has been used to justify the administration of high doses of opioid analgesics in order to relieve pain and other severe symptoms even at the risk of hastening death. DDE allows physicians to administer adequate palliative care to patients while still being opposed to physician-assisted suicide and euthanasia. As exemplified in the palliative care context, DDE was formulated in the attempt to deal with situations of radical moral uncertainty. DDE arises in instances where prudential reasoning, distinguishing between a virtuous and non-virtuous act, is at an impasse. In other words, the need for DDE arises because of the impossibility of using *phronesis* in order to determine the good means to a particular end. The apparatus of prudential reasoning is jammed because of the “ontological uncertainty” that comes to exist regarding the consequences of one’s actions. DDE provides a solution to this impasse by arguing that even though the act of killing is wrong, if it is an unintended consequence of an action intended to alleviate distress, then it is not considered killing. Through analyzing the mechanism of DDE in palliative care I shall demonstrate in this paper how DDE operates through temporarily suspending prudential reasoning while simultaneously providing a mechanism for its resuscitation.

# **Caring for families at sudden cardiac death: A balance between closeness and distance**

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Out-of-hospital cardiac arrest (OHCA) is a lethal health problem that affects more than half a million people in the United States and Europe each year. As resuscitation attempts are unsuccessful in most of the cases, ambulance professionals often face the needs of bereaved family members. Decisions to continue or terminate resuscitation attempts at OHCA are influenced by factors other than patient clinical characteristics, such as the personnel’s knowledge, attitudes, and beliefs regarding family emotional preparedness. Research exploring how ambulance personnel are affected by family dynamics and the emotional context, and how they are able to provide care for bereaved family members is sparse. It is also a lack of research into why ambulance professionals sometimes administer physiologically futile cardiopulmonary resuscitation (CPR) to patients with cardiac arrest to benefit family members. This way of meeting families’ grief reactions implies ethical problems.

Based on an empirical study of ambulance professional’s experiences of caring for families when patients suffer cardiac arrest and sudden death, and an ethical analysis exploring arguments for providing physiologically futile CPR, the issue of caring for bereaved family members in ethical good and bad ways is explored. The empirical study results show that ambulance personnel experience a concomitant responsibility, sometimes failing to prioritize between responsibilities as a result of their own perceptions, feelings and reactions. Moving from patient care to family care imply a movement from well-structured guidance to a situational response where the personnel are forced to balance between interpretive reasoning and a more direct emotional response at their own discretion. With such affective response in decision-making, the personnel risk erroneous conclusions and care relationships with elements of dishonesty, misguided benevolence and false hopes. The ability to recognize and respond to people’s existential questions and needs is essential, and dependent on the ambulance personnel’s balance between closeness and distance, and on their courage to meet emotional expressions of the families, as well as the personnel’s own vulnerability. A need for ethical competence is invoked by the presence of family members, placing great demands on mobility in the decision-making process, between medical care of the patient and caring for family members.

The conclusion is that the strategy of ambulance professionals in the care of bereaved family members should be to avoid additional suffering by focusing on the relevant care needs of the family members and provide support, arrange for a peaceful environment and administer acute grief counselling at the scene, which might call for a developed ethical caring competence. Opportunities to reflect on these situations within a framework of care ethics, continuous moral education, and clinical ethics training are needed. Ambulance personnel also need training in awareness of the needs of families suffering sudden bereavement, as well as support and help to deal with personal discomfort.

**Professional license?**

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There has been much debate over whether a medical professional may refuse to participate in patient treatment that is at odds with that professional’s conscience, in most cases with her religious conscience. Sometimes the claim is cast as a very general right of conscientious refusal, applicable to all people in all employment contexts; sometimes it is cast as a claim specific to medical professionals and their professional judgments. I argue that at issue are the kinds of *reasons* a professional, especially a medical professional, may use in making a professional decision. I argue (1) that there is no general moral right of conscientious refusal, and (2) that the nature of professionalism does not support a professional right of refusal. I claim that professionals must give *professional* (rather than *personal*) reasons for what they do or refuse to do, and that these are reasons that must be capable of being seen *as* professional reasons by all (or at least a substantial majority of) members of the relevant profession. Religious reasons, as well as other reasons, including some moral reasons, will not pass the “professional reasons” test.

I argue further that when, as is sometimes inevitable, the judgments of a medical professional incorporates values, the reasons invoked to support such values must be reasons that all citizens could (not necessarily would) accept, each from her own religious or moral standpoint. Reasons that would require citizens to adopt a new religious or general moral view are not appropriate. The value-laden reasons a medical professional gives must be what John Rawls has called *public* reasons. This requirement applies to medical professionals because they are licensed by the state to exercise monopolistic authority with regard to crucial and often live-saving activities; moreover, much of the educational costs and income stream of medical professionals comes directly or indirectly from the state.

The practical implications of my analysis will displease both the left and the right. Any adequate account of conscientious refusal must be content-neutral, i.e., must not depend on the content of the refuser’s religious or moral beliefs. The content-neutrality of my view yields outputs troubling to each side of the political spectrum. Moreover, my analysis sets the stage for other questions. That there is no *right* of conscientious refusal does not entail that there should be no *accommodation* of conscience, either within a single medical institution or by permitting religious medical institutions (though publicly licensed, funded, and so forth) to limit their offerings by reference to religious teachings. My analysis entails that accommodation is not a right but a matter of sensible public policy. Here, I propose a particular balance among competing interests, roughly, that accommodation is acceptable when it neither interferes with an institution’s provision of services to patients nor reflects invidiously on the equal moral status of any patient. The specifics of my proposal will be contested. That is less important than the thrust of my analysis – that institutional accommodation of conscience concerns good social policy, not fundamental individual rights.

**Ethical issues of memory intervention in Worst case bioethics**

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One very important core faculty associated with brains is memory. Memory plays a decisive role in our lives insofar as it (a) relates to the core of who we are in the most direct way (identity and continuity of the self), (b) helps us building an interpretation of us and our environment (it gives us a story, hopefully a coherent one, of ourselves and our world by interpreting, constructing and condensing life experiences), and (c) gives us a sense of continuity and connection to ourselves and to others. Taking into consideration the role memory has in our lives, it can be argued that it also plays a crucial role for our moral life. In this regard, our past experiences enable us to find a narrative of how we come to be who we are now, to learn and interpret the moral of our experiences, and to act in appropriate moral ways. It is because of all these characteristics that the ethical implications of memory interventions aimed at dampening or enhancing memories related to war, disasters and similar difficult situations should be taken seriously. In this paper I start by highlighting the importance of memory for our moral life and general wellbeing. After this I move on to discuss some of the possible interventions as well as interventions under research for memory modification, in particular I focus on the case of dampening memories to treat post-traumatic stress disorder and memory enhancement as a way to preserve memories of events like wars and disasters. Then, I assess different ethical aspects of these memory interventions for both individuals and society. The paper ends up with a suggested framework to assess the permissibility of memory modification interventions in the previously discussed scenarios as well as highlighting the difficulties of determining when our memories should become the subject of biomedical and other non-therapeutic interventions.

**DNA Identification of human biological material from Mass Disaster: some ethical issues**

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Mass disasters can involve natural (e.g. earth quakes, volcanoes, avalanches, hurricanes, and tsunamis) or non-natural catastrophes (e.g. transportation accidents, terrorist activities, wars, or political crisis). Each incident has its own characteristics and will involve a different approach. Depending on the nature of the event, the safeguarding and collection of forensic evidence will also have to be considered as part of the field response procedure. Forensic DNA profiling is increasingly becoming an important tool in the individual identification in the aftermath of mass disaster. While forensic geneticists are often not included as first responders, DNA sample collection and a strategy for DNA-based victim identification needs to be part of the community’s preparedness plan, in fact the preparedness plan of the laboratory needs to include policies for family notification, long-term sample disposition, and data archiving.

There has been very little systematic effort to identify and analyze the major ethical and policy challenges associated with this new use of genetic technology. One of the objectives of the forensic investigation of human remains is to identify the remains and, if possible, return them to the family of the dead person. This objective helps family members by ascertaining the fate of their relative and allowing the remains to be handled in a culturally appropriate manner, thus enabling the families of the missing to mourn their loss. Ethical issues are associated with the use of DNA identification, because information contained in a person’s DNA is sensitive and it is a unique identifier and may contain information about a person’s family and intimate associations. International law does not have any specific provisions for protecting genetic data in mass disaster. International humanitarian law and international human rights law recognize the need to provide special protection for persons affected by armed conflict. However, these bodies of law contain only general principles relating to confidentiality, privacy, non-discrimination, and human dignity that can be applied to the protection of genetic data. It seems important to evaluate how to deal with: incidental findings (e.g. misattributed paternity/maternity), ethical acceptance of secondary uses of the biological materials collected (e.g. sample storage and use), use/misuse associated with the creation of large genetic databases, and last but not least with issues related to privacy that has to be rigorously protected to ensure the respect of human individual right.

**Canguilhem and the ethical-philosophical character of life sciences**

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This essay aims at pointing out that the concept of vital normativity of Georges Canguilhem (1904-1995) is crucial to highlight a central issue with regard to challenges to current biological knowledge. This concept, while stating that value is an irreducible property of life, presents an essential question concerning not only the transformation of the sciences of life, but also the relation between science and philosophy.

The controversy related to biological knowledge is linked to important problems concerning the models of health assistance. From the epistemological point of view, the great issue is the duality that separates body from mind. From the point of view of health practices, this duality shows up in the persistency of a technical model, which dissociates assistance from related social, cultural and affective realities, with ethical implications. Different conceptions should be applied so that this tendency could be reversed. At the same time, attempting to obtain them, looks like rowing against a powerful stream. The scientific model of health, in spite of the fact that it generates serious contradictions, has the power to be operative, instrumental and utilitarian. In this context, it is decisive to reassess the relation between science and philosophy. Canguilhem’s reflection on the sciences of life has a philosophical nature that is radically important to the prospect of transforming these sciences.

The concept of vital normativity, proposed in his 1943 thesis *The Normal and the Pathological*, is at the centre of Canguilhem’s work. He pointed out as a problem for biology the evidence that life has the property of creating norms to persevere. What would be the characteristic peculiar to life, from the most elementary kind, to perform some mode of discrimination between what is either favourable or unfavourable to it? Physical chemistry has not explained this irreducible attribute of the living being condition.

The same controversy can be found in the discussion on the relations between brain and thought. In a conference given in 1980, Canguilhem reaffirmed that an unconscious position of value was a fundamental feature of the living being and was at the origin of human thought. He considers it impossible to equate the brain with either an electronic machine (computer) or a chemical machine. In order to elucidate what thought is, one must take into account the idea of value, desire or will. Cognitive processes in living beings include some kind of subjectivity. Questions not answered up to now concerning either neurosciences or the definition of life testify to the up-to-dateness of Canguilhem’s perspective. Concerning neurosciences, one important question is the ambiguity between the exteriority of a mechanism and the interiority of the living being’s experience. The dualistic character of this ambiguity is related to the impossibility of a short and universal definition of life that could be accepted by the different sciences.

To deal with these issues changes would be necessary in the philosophical conception of what man is and what man’s relation to knowledge is.

**The tribunal of modern life: The case of UZ Brussels in the light of Odo Marquard’s discussion of autonomy and theodicy**

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In 1999, in a hospital in Brussels, Belgium, a pre-natal test was performed. The test examined the enzymatic activity of an embryo, in order to prevent the birth of a child who would from the rather rare but all the more severe Sanfilippo syndrome. Since the parents already had a daughter with the Sanfilippo syndrome genetic disorder, they wanted to prevent their new child from being born with the same disease. The tests carried out at UZ Brussels came back negative and the parents decided not to abort the pregnancy.

Alas, when the child was born she was nevertheless found to have Sanfilippo syndrome which deeply disappointed the parents. In 2004 they took legal action, charging that the hospital had been negligent in failing to diagnose the handicap, thereby exposing the child to a life of suffering. In fact, their charge was not that the baby was disabled, but that the child was born at all. On top of that, the charge was brought in the child's name, and so effectively the child was suing against its own birth

At first glance, this only seems to be another example of Belgian surrealism, but there is much more at stake here; this situation demands moral understanding and philosophical analysis rather than political irony. Although several cases from all over the world are known, since it was the first time a Belgian court deliberated a so called ‘wrongful life’ case, the case was unique for Belgium. In the UK, Germany, the US or France, cases were already in court, but there is a general lack of consensus in jurisdiction: some courts do recognize it as a legal case, others don’t.

This remarkable and precarious case invites us to analyze the complex motives surrounding the court’s decision and the parents’ battle for justice. Of course, many perspectives are useful here to analyze the complexity of the case: ethical, philosophical, judicial, etc. In my presentation, I will use the theory of the German philosopher Odo Marquard to shed light on this unique case for Belgian society. In this case, not only has life itself become the subject of the judicial logic Marquard writes about; it is also an illustration of our continuous struggle to avoid evil or suffering in modern life In several of his articles and books, Marquard develops an interesting thesis which turns our idea of autonomy upside down: autonomy, he argues, is not an enlightened gesture against Christianity but an inherent motive of theodicy. In this gesture, I will argue with Marquard, we cannot deny that medicine and theology still meet, notwithstanding modernity. Consequently, the case of UZ Brussels does reveal an ‘old’ problem, rather than it simply witnesses of contemporary ethical dilemmas.

**Concept of Governance in Dual-Use Research**

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The rapid advance of life science within the context of increased international concern over potential misuse of findings has resulted in the lack of agreement on the issues of responsibility, control and collaboration. This progress of knowledge outpaces the efforts of creating moral and legal guidelines for detection and minimizing of the risks in the research process. There is a need to identify, analyze and address ethical and normative aspects of dual-use research.

This presentation will focus on issues of safety and global collaboration in life science research by highlighting the importance of openness, enabling policies and cooperative governance. These safeguards are believed to reduce the risks related to misuse of science while enabling the important research to move forward. The three necessary moves in addressing the issue of security in life sciences will be suggested: move from constraining to enabling types of policies, move from secrecy to openness and move from state-driven government to the governance of science.

The top-down approach to science results in contradiction between the global character of experiments and local character of rules, difficulty in predicting the outcomes of an experiment, dominance of political and ideological ideas in policy-making, and unfamiliarity of legislative bodies with science. In addressing the issue of security it is important to stress the necessity of the bottom-up approach to control of dual-use research that fosters peer collaboration and attempts to provide a framework within which scientists can operate. Enabling policies will result from efforts of promoting a culture of shared responsibility that recognizes a variety of stakeholders in research and involves them in the process of evaluation.

The failure to maintain openness in research may result in undermining the process of peer-evaluation while creating obstacles for progress and innovation. Maintaining openness carries the connotation of global cooperation and can be the way of upholding the component of social responsibility. Openness can be supported by international conventions on the topic of biosecurity.

There is a need for transition from the hierarchical role of state agencies as the main normative bodies to the networks with increased participation of non-governmental groups. In this manner delimitations between state and society, between experts and civilians should decrease, giving way to participation of multiple individuals and institutions in the process of policy-making. The implementation of the governance concept may result in establishing an international standing committee of science and ethics experts to overview dual use developments.

**Narratives of Collective Suffering**

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Elsewhere (Edgar 2007)I have argued that modernist narrative forms, that disrupt the sense of easy story-telling or meaningful and fulfilling endings, are uniquely appropriate as means for articulating the suffering associated with severe chronic conditions. In this presentation, I will develop these arguments in order to explore the nature of narrative and representation with respect to ‘disasters’, where large numbers of otherwise unrelated individuals, or where communities of various sizes are affected. Such events would include large scale traffic and other travel accidents, natural disasters and industrial accidents. By examining certain historical and recent cases, including the 1966 Aberfan mining disaster, and their representation in narrative and photography, the paper will seek to articulate criteria according to which successful and successful, or appropriate and inappropriate, forms of representation may be judged. It will be suggested that narratives and other forms of representation need at once to embrace the possibility of explanation and the ascribing of meaning to the events, and yet, in order to avoid easy, trivial or exploitative interpretation, to highlight the arbitrariness and ultimately meaninglessness of such events.

**Ethical issues of dual-use research of concern in Switzerland**

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Dual-use research of concern (DURC) refers to research that may be used for good and harmful purposes. The term dual-use initially described security threats associated with the use of engineering and information technologies for military purposes. It was only recently that the dual-use potential of life science research entered the spotlight, when in 2002, merely months after the anthrax attacks in the US, scientists published how to re-create polio virus from scratch based on its published sequence. Their research initiated a controversial debate on biosecurity and biosafety threats associated with life science research. Since then further examples of dual-use life science research have provoked an international echo, including the recent case of novel man-made influenza strains. In November 2001, research teams from the Netherlands and the US announced to have mutated the bird flu virus yielding flu strains that combine the virulence of the bird flu and the transmissibility of the seasonal flu. Publication of these influenza studies has been halted due to fears concerning misuse of the virus by rogue scientists.

So far, US-based scientists and security experts have dominated the debate around DURC in the life sciences. Few ethicists have joined the discussion. An interdisciplinary examination of the topic using empirical data that goes beyond general ideas about DURC is urgently needed. The study I intend to conduct will collect the much needed empirical data on the awareness, views and perspectives of the various Swiss actors (and possibly international stakeholders) involved based on realistic case scenarios. The specific aims of the study are: (1) to identify national and international guidelines and ethics codes for DURC; (2) to collect information regarding the level of regulation of DURC in the life sciences at universities, scientific societies, and funding bodies, and (3) to study the awareness and views of the topic of DURC among scientists using concrete vignettes and real and hypothetical cases identified in the literature and through interviews. The collected data will help to ensure an accurate, accountable and evidence-based process for identifying appropriate governance options in Switzerland and offer a basis for a subsequent normative ethical analysis of the DURC dilemma.

**Clinical Care of Human Life and its Reasonable Limits**

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Appropriate medical treatment and nursing care should be made available to all who need them. However, the duty of care is not absolute when it comes to demanding specific treatments to cure diseases or to prolong human life. The medical profession and the State are not bound to go to unreasonable lengths to provide every possible treatment regardless of cost, so long as basic comfort, care, nutrition and hydration are made available. The drawing of the line between where treatment should be given and where it need not be given is one of the most perplexing moral dilemmas that doctors and competent patients have to face. Often there is no one correct answer since only general principles are at hand to be applied on a case by case basis. Consultation among colleagues may facilitate the task of assessing the balance of likely benefits and risks of harm following surgery or other medical treatments. Doctors in some cases need to reassure their patients and relatives that surgical or continuing medical intervention is not in the best interests of their patients. An elderly competent patient may not want to have surgery: doctors and family members should respect this human and eminently personal decision.

 Doctors’ unreasonable fears of being sued for malpractice do not contribute to making the best medical decisions:-- it is not in the public interest for doctors to be worried by such concern. States should have laws that permit due respect be shown to elderly patients’ wishes to refuse surgery or burdensome treatment without doctors being put at risk of legal action against them. The assumption should be that doctors, medical staff and nurses exercise their professional duties in a morally responsible way unless the contrary can be proved beyond reasonable doubt. Refusing disproportionate means of treatment is not to be confused with suicide or euthanasia. However, refusal by patients to take reasonable and readily available medical treatments that have a good chance of saving their lives does raise serious ethical concerns.

The use of sedatives is often ethically required for patients who are terminally ill. Keeping the dying aware is important unless they need medication or sedatives that may leave them unconscious for a period of time. However, the use of sedatives for patients close to death should not be considered terminal sedation – a term best avoided in professional health care circles.

Dying patients appreciate the opportunity to converse with others. The elderly in nursing homes who lack chances to talk with others die sooner. When relatives, friends, nurses or others greet these patients with a smile and a few cheerful words, their spirits and sense of dignity are lifted. Finally, the elderly may appreciate a visit from their own minister of religion or pastoral care worker – such visits may be a source of comfort and peace, especially for those who are nearing their end of life on earth.

**Synthetic Biology: What can be learned from Worst Case Scenarios?**

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The career of new and emerging science and technology (NEST) in scientific, political and public debates is related with a specific type of techno-visionary communication as has been pointed out by several STS researchers, ethicists and technology assessment practitioners at the occasion of nanotechnology and human enhancement technologies. Synthetic Biology is in some respect a similar case: high potentials and expectations but also far-ranging fears and concerns, a very early stage of development, lack of knowledge about future developments, applications and their impacts and consequences as well, high interest of civil society organisations and of funding agencies.

Many fears and concerns are already considered, partly reminding to the GMO debate and addressing issues such as bio-safety and bio-security. It is still unclear whether there might be completely new (possible) risks. It seems that arguments and positions of the ‘Playing God’ type and the human ‘hubris type’ might become intensively discussed in public debates. It is not easy to identify worst case scenarios beyond mere speculation because of lack of knowledge. Probably the worst case scenarios which have been brought forward in the field of nanotechnology and nanobiotechnology will be reconsidered in the field of Synthetic Biology: the ‘ultimate catastrophe’ diagnosed by Jean-Pierre Dupuy and the ‘why the future doesn’t need us’ scenarios by Bill Joy. Both of these dystopian views have to do with loss of human control over technology, and both of them could be related with bio-safety and bio-security issue mentioned above by thinking them to the extreme.

The question I want to deal with in my paper is whether we could learn anything from those worst case scenarios, and what this could be. Some might think about consequences in the light of the ‘Imperative of Responsibility’ by Hans Jonas or regarding the Precautionary Principle. My answer will be, as far as I can see today, sceptical concerning this type of conclusion because of the mere speculative nature of those scenarios.

However, building on the recent debate on the ‘speculative nano-ethics’ I will then show that, in spite of this diagnosis, we can learn from speculative worst case scenarios but in different respect. An ‘explorative philosophy’ could uncover anthropological presuppositions of those worst case scenarios, allow for hermeneutical insight into hidden images of the relation between technology and life, or between humans and technology, possibly relate worst case scenarios of Synthetic Biology with grand narratives of humankind and so on. By doing this we obviously could not learn anything about the future of Synthetic Biology and its implications on society, but we probably would learn a lot about ourselves today. This seems to the most promising insight of investigating worst case scenarios. It reflects that all the stories which are told and debated over the future at the occasion of NEST are result and part of our present thinking.

**The Human Right to Health and Democratic Institutions**

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It is important to distinguish temporary crises that require immediate aid such as devastating earth quakes from long-term crises brought about by extreme poverty, intractable conflict and the like. In general, I am concerned with an ongoing health crisis—the state of poor health in nations that lack the resources to provide their citizens with adequate heath care. I assume for the sake of argument that there is a human right to health. In particular, I am concerned with the role of democratic decision-making in the implementation of the right to health. Norman Daniels correctly points out in *Just Health: Meeting Health Needs Fairly* that we cannot simply derive specific health care entitlements from a human right to health. Daniels argues that health care entitlements should be determined on the basis of principles of justice that are applied through a process of deliberation, which he calls “accountability for reasonableness.” On his model, policies that limit health care must be based on rationales that are publically accessible and reasonable. In addition, the policies must be open to revision and regulation. Daniels claims that accountability for reasonableness facilitates democratic decision-making, but he does provide an argument for the role of democracy in creating health care entitlements.

I argue that democratic decision-making regarding the creation of health care entitlements is crucial for the implementation of the right to health. At a practical level democracy, as some have argued, enables people to demand health care entitlements and to hold public officials accountable. At a theoretical level democratic decision-making regarding the availability of health care resources is an extension of individual autonomy in individual health care decisions. In addition, the most plausible philosophical justifications for the right to health also justify a right to democratic decision-making in the implementation of the right to health. Hence as resources are made available to poor nations through international aid in an effort to fulfil the right to health, the process of implementing that right by creating specific health care entitlements requires democratic decision-making.

Unfortunately, some of the nations most in need of aid lack the social conditions and institutions necessary for democratic decision-making. In such cases implementation of the right to health requires efforts at building the sort of civil and national institutions that can support health care entitlements and democratic decision-making. This creates ethical issues that need to be addressed. Significant cultural changes may be needed, and this can give rise to charges of cultural imperialism. In addition, emphasis on cultural change makes it difficult for international humanitarian agencies such as the Red Cross and Red Crescent, as well as the World Health Organization to maintain neutrality regarding local political and ideological disputes. In the end, however, I argue that these issues do not provide compelling objections to the need for creating democratic institutions related to the provision of health care.

**Distributing health care according to need – what concept of health care need is needed?**

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Scarce resources make priority setting in publicly financed health care systems unavoidable in worst case scenarios as well as in day to day health care. The underlying assumption for priority setting is that there is a gap between individuals’ demands for health care and scarce resources. This raises difficult ethical questions on how to distribute health care services. One generally considered plausible way to do that is according to people’s needs for health care. As intuitively appealing this suggestion might appear at first glance it is not clear what giving care according to *the need principle* actually means.

To characterize a plausible principle of health care need it seems as a reasonable starting point to explore the conceptual underpinnings of the concept of need. I shall focus on three different views on how to understand needs which are found in the literature, (i) need in an instrumental sense, (ii) need in a categorical sense, and (iii) need in a fundamental sense.

The crucial difference, usually stressed by writers, is between those who claim that *all* needs statements are instrumental (takes the form of “x needs y in order to z”) and those who deny this claim and argue that some needs statements are categorical or fundamental (takes the form “if x really needs y then x needs y period”). The latter pair derives its normative force from the necessary condition that harm should be avoided while the former derives its normative force from the advancement of well-being. Is this basically the same claim or are there reasons for choosing one over the other in the project of constructing a concept of health care need?

Two interrelated points will be discussed in this presentation. First, it will be made explicit that these three theories share the same conceptual underpinnings of the concept of need. I argue that they all take the instrumental form. Second, I shall discuss whether there are any important differences in the element(s) from which each concept derives its normative force.

Finally, it will be concluded that in the project of constructing a concept of health care need each theory make fruitful contributions to construct a plausible understanding of the concept of health care need and are, in this context, rather three different aspects of the same thing – the concept of health care need.

**Humanism as a transcendental basis for intellectual-disability policies and studies**

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In societies that are ideologically and politically committed to the notion of equality it is necessary to choose a criterion for the kind of beings who merit equal respect or equal treatment. Historically, men, citizens, those with economic means, those with defined religious views, and those with defined physiological features have been included in the community of equals, while others have been excluded. Enlightenment philosophers extended the sphere of equality to all rational beings and to all sentient beings; and their critics have used membership in the human species as the measure of dignity and moral worth.

One group whose inclusion in the community of equals has not traditionally been self-evident but has gained momentum during the last decades is constituted by human beings with intellectual disabilities. On what grounds can they be included? On what grounds can they be excluded? Answers to these questions are crucial for policy decisions concerning the treatment of people with intellectual disabilities and informing popular attitudes towards them.

This paper studies answers to the question of including people with intellectual disabilities into the sphere of equal moral consideration and respect. The question will be approached by philosophically examining the views presented by Jeff McMahan and Eva Feder Kittay in an exchange of views during the last decade. McMahan and Kittay represent the opposite poles of the debate, and it is therefore instructive to see how their arguments and counterarguments proceed.

The conclusion will, according to my working hypothesis, be that the only way to grant people with intellectual disabilities an entitlement to equal consideration and respect in policy making and legislation is to assume that humanity as a transcendental principle is the only, or at least the most important, yardstick of moral status.

**A Worst Case Balancing Act: Peak Oil, Biofuels and Synthetic Biology**

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Several significant threats may face humanity in the near to medium-term future. Population is growing rapidly, and may increase by 50% from current levels within a few decades. The demand for land, water and food will increase proportionately, yet useable land and agricultural output may be reduced by climate change. Demand for oil will increase with population – in addition to transport requirements, fossil fuels are used in numerous consumer products, including plastics, paints and cosmetics. Peak oil, the time when oil extraction reaches a maximum, to be followed by a decline in output until resources are used up, is likely to occur within the same time frame. This could result in a transition back to an earlier form of civilisation; if such a transition occurs, it is likely to be traumatic.

It would appear to be an ethical imperative that some replacement is found for fossil fuels, while also addressing climate change. Research into biofuels may offer the potential for both. Here biomass (plants, industrial waste, microbes, algae, etc) is used as a source of fuel, and some of the fuels produced have significantly lower greenhouse gas emissions than fossil fuels. In addition, biofuels are a renewable energy source. The Nuffield Council on Bioethics, however, has described current biofuels policies as unethical. One concern is the food vs fuel debate – the fact that land used for biofuels could otherwise be used for food. Biofuel production was a factor in the food riots of 2008. The current technology has also caused significant deforestation, and it poses a threat to biodiversity, threatening numerous species with extinction. Also, while some modes of biofuel production can help reduce greenhouse gas emission, others can increase it by as much as 2,000%.

There is a possibility that advanced biofuels technology, currently at the research and development stage, may help solve some of the ethical issues. Synthetic biology, the nascent attempt to create new forms of life and engineer current life-forms to required specifications, may allow new plant species to be engineered which can produce biofuels more efficiently. Also, algae can be engineered to act as fuel sources; certain species could be cultivated at sea or in areas of unproductive land. These fuel sources are not commercially viable, currently, but synbio could make them so.

But synthetic biology has its own ethical problems. It is the ultimate dual-use activity, with the potential to be applied for great good or great evil. Beneficial advances in one area of synbio could be applied in different areas of synbio research for extremely negative purposes, such as the creation of biological weapons of mass destruction. DIY biology/biohacking is a significant issue – it may grant great destructive power to interested members of the public. There is also potential for disaster due to scientific unknowns and engineering errors. Thomas Douglas and Julian Savulescu have referred to synbio as a possible blueprint for humanity’s destruction.

The advent of synbio could help to solve the fossil fuel crisis, replacing non-renewable fossil fuels with cheap, renewable energy. Or it could add to the above threats, causing a coming together of worst case scenarios of Shakespearian proportions: "When sorrows come, they come not single spies, but in battalions" (Hamlet).

**Physicians’ attitudes towards advance directives in England and France: National differences or common policies?**

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Patient-autonomy is an essential element of modern medical practice. Changing demographics and the increasing number of patients with dementia raise question about how patients’ wishes should be taken into account when they are no longer able to express themselves. One instrument to this is the advance directive, whose legal recognition was advocated by the Council of Europe at the beginning of 2012. Yet, although most Western countries, such as England and France, have adopted legislation on advance directives, they are only rarely implemented in practice. In spite of these legal requirements, decisions regarding treatment withdrawal at the end of life remain an urgent problem for physicians.

In this paper I will explore the attitudes of English and French physicians towards advance directives in order to achieve a better understanding of discrepancies between normative standards and their practical implementation. Using semi-structured interviews, I investigated the ways that English and French physicians reflect on the advantages and disadvantages of advance directives. The comparison highlights different value systems and a different understanding of the concepts of autonomy, social responsibilities and solidarity.

Attributing a high value to respect for patient autonomy, most English doctors express concerns regarding the authenticity of an anticipated will. They therefore consider it preferable to discuss the patient’s wishes with them, rather than resorting to signed documents. In France, most physicians do not want their decisions to be led by signed documents because they are afraid of losing their professional autonomy and their responsibility towards the vulnerable person. Alluding to a culture where most physicians are still attached to excessive medical interventions, even at the end of life, some French doctors emphasise the importance of doctors learning when to judge treatment to be disproportionate, rather than turning the decision over to the patients.

The findings suggest that doctors in each country have different needs regarding end-of-life decision-making which are related to their respective cultural, political and philosophical tradition. Seemingly, these needs are not necessarily covered by implementing advance directives. The question arises, then, whether policy makers in each country should first concentrate on specific requirements, such as improving conditions for doctor-patient communication or sensitising doctors for excessive, disproportionate treatment, before trying to apply an internationally recognised instrument. Once these national requirements are satisfied advance directives might be an additional element in improving end-of-life decision-making. Comparing countries and gaining an insight into their particularities enables us to develop a broader knowledge of the problems regarding respect for patient autonomy and thus to generate a common understanding of different needs. Such understanding should facilitate the creation of common policies, like that sought by the Council of Europe.

**How is defined the best interest of society when precautionary principle is applied ?**

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Precautionary principle is explicitly mentioned in EU legislation focused on environment. The use of precautionary principle as moral supporting method for decision making process is based on EC Communication on the precautionary principle (2000) where this principle is discussed and applications for consumer health protection and environment are described. The procedure for risk assessment is based on: 1) risk evaluation; 2) risk management; 3) risk communication. The precautionary principle is used for different purposes such as identification of potential negative effects, scientific evaluation and scientific uncertainty. In medical area the precautionary principle was invoked as decision method in pediatry (Hyder, A., Juul, N. *Games, Gambling, and Children: Applying the Precautionary Principle for Child Health .*Journal of Child and Adolescent Psychiatric Nursing, 21(4), 202-204(3) 2008), vaccinology (Crowcroft, N., Elliman, D. *Vaccination and anesthesia: the precautionary principle is to vaccinate*. Paediatric Anaesthesia, 17(12), 1216-1218(3), 2007) as well as in cancer prevention (Hardell, Lennart. *Pesticides,soft-tissue sarcoma and non-Hodgkin lymphoma - historical aspects on the precautionary principle in cancer prevention.* Acta Oncologica, 47(3), 347-354(8) 2007).

In this paper I will analyse the opinions of the European Group for Ethics in Science and New Technologies (nr.15-24) to highlight the controversies related with the best interest of society and to understand the development of the precautionary principle framework for this particular aspect. In this context I will trace back the EU controversies regarding how to use in practice precautionary principle and I will insist on ethical values to limit or to validate such approaches. Generally speaking the precautionary principle in relation best interest of society was mentioned more in area of new and emerging fields of science and new technologies, linked with solidarity and equity principle.

**Human capabilities, mild autism, deafness and the morality of embryo selection**

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A preimplantation genetic test for one or more Autism Spectrum Disorders might be developed in the foreseeable future. Recently, the philosophers Julian Savulescu and Guy Kahane claimed, among other things, that there are strong reasons for prospective parents to seek to prevent the birth of children who are disposed to Autism or Asperger’s Disorder. In this paper we will criticize this claim.

We will discuss the morality of selection *for* mild autism in embryo selection in a hypothetical IVF situation where Preimplantation Genetic Diagnostics is performed and compare this with a similar selection for congenital deafness. To do this we first discuss some human differences that are relevant. We then introduce the Principle of human Capabilities (PC) and compare this principle with the Principle of procreative Beneficence (PB) introduced by Savalescu and Kahane. We apply the two principles to selection for mild autism and selection for congenital deafness. We argue that PC allows for the selection for mild autism but rules out selection for congenital deafness. PB will not give clear answers; the ruling of PB depends to a large extent on expected social, cultural and political developments.

We will introduce and discuss another intuitive principle, the principle of human flourishing (PF) and compare it with PB and PC. We will discuss arguments for the value of autism in our world and argue that persons with autism may flourish and have a reasonable good life. Under PC and under PF it is morally permissible to select for mild autism in the PGD situation. To select for congenital deafness is morally wrong under PC and a clear answer is neither given by PB nor PF. The wider PB (WPB) gives only one very robust recommendation: procreate with someone rich. We will argue that PC is preferable to PB and WPB as well as PF.

**Clinical Responsibility When Refusing to Treat with Donor Gametes**

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Donated gametes can be used to help parents avoid passing on genetic conditions that cause suffering and disability. Clinics offering treatment with donated gametes are governed by the Human Fertilisation and Embryology Act, which stipulates that they must consider ‘the welfare of any child who may be born as a result of the treatment […] and of any other child who may be affected by the birth’ (Human Fertilisation and Embryology Act (2008), section 14 (2), available at <http://www.legislation.gov.uk/ukpga/2008/22/contents>). The accompanying Code of Practice states that the treating clinician must take into account a patient’s ‘medical history, where the medical history indicates that any child who may be born is likely to suffer a serious medical condition’ (Human Fertilisation and Embryology Authority Code of Practice, section 8.10 b) iii), available at <http://www.hfea.gov.uk/5473.html>). While it seems clear that there is a legal obligation to avoid the birth of such children, it is not clear whether clinics are only morally responsible for children born as a result of *treatment*, because given that putative parents seeking to avoid passing on genetic condition may be fertile, children could be born as a result of a clinic’s *refusal* to treat.

This paper will argue that fertility clinics already concern themselves with the welfare of people other than the patients themselves (for example the patient’s partner, the child who will result from treatment, and any other child who will be affected). One potential objection here is that the people whose welfare clinics already consider *are* people who can be considered patients themselves. This may be true in some cases, but it is not clear that the child who will be born from treatment is a patient *at the time of treatment*, given the view of the legal and moral status of gametes suggested by other practices (such as their routine destruction). It is perhaps even harder to see how an already-existing child is a patient in such a way.

Given this, the paper will argue that to be consistent, clinics must also consider the welfare of children who may be born as a result of a refusal to treat. It might be argued here that clinics should move in the opposite direction in order to achieve consistency, such that they *cease* to account for the welfare of these groups who have been shown not to be patients, but this paper will argue that the consequences of failing to account for the welfare of children in gamete allocation are too dire to countenance. This gives clinics a reason to prioritise the fertile with heritable genetic conditions over the infertile where gametes are in short supply even where this means that the infertile may not have the opportunity to reproduce at all. This conclusion takes seriously Savulescu’s argument that ‘doctors [should] be influenced by reasons for action which go beyond the welfare of the individual concerned […including] the welfare of others’ (Savulescu, Julian 1999. ‘Should doctors intentionally do less than the best?’ in *Journal of Medical Ethics*; 25).

**Teaching responsible conduct of research in the life sciences and the hidden curriculum** Kakuk, Péter

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The last decade showed an increasing international interest in establishing the norms of scientific research. Current challenges to the integrity of science in the form of financial conflict of interests, data-management, abuse of authorship, research misconduct, and fraud has been the focus of ethical and policy analyses. New courses entered the curriculum of universities under the title of Responsible Conduct of Research and the ethics of science. There are significant international approaches for establishing an ethical a policy consensus for newly needed scientific norms and also for educating future scientists. However, there is conflict between the explicit values and norms embedded in these courses and norms and values young scientists acquire via their professional socialization. In this presentation I would like to focus on this problem of the hidden curriculum with asking the question of how our new educational approaches are suitable to change the everyday practice of scientists.

**Experiences from the Heart of Jenin project**

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This talk is about the experience after the organ transplantation which took place from Ismael Khateb’s son to Israeli children. Organ transplantation across border of military and political conflict is not common. After the transplantations he felt a familial tie with those families whose children received his son’s organs. In this session Ismael Khateb will thematize the bodily basis for a relationship with those who were strangers and even at the “other side” before. Now he works with young people in different cultural projects and established a cinema in Jenin. For moments hostility might be overcome. New hopes and initiatives to further peace keeping, cultural activities, and personal relationships can develop.

**Problems associated with reproductive technologies - The best interest of a surrogacy-born child versus the best interest of the surrogate mother's children: Finding a compromise for contradicting interests of children of one mother.**

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A basic challenge in bioethics is the identification and the resolution of issues, which consist of people with contradicting needs and interests. This challenge is highlighted in the case of a surrogate mother, her own children and the needs of the child she will give birth to and will transfer for adoption. The law in Israel explicitly refers to the best interest of three persons in this situation: the child to be born, the adopting parents and the surrogate mother. The law does not address the surrogate mother's children. This omission is acute considering the clauses in the law prohibiting married women and women without children from becoming surrogates. Thus, surrogate mothers are by definition single mothers to children, and commonly of young age.

The surrogate mother’s own children, which are at the basis quite vulnerable as being in a single parent family, may be further exposed to hardship associated with their mother’s direct and indirect difficulties of the pregnancy. They may be hit by social stigmatization and from the need to assimilate in their world the role of the genetic parents and the disappearance of the baby sibling. Medical complications, prolonged hospitalizations and post-partum depression. The law has to address the interests of surrogates' children.

1. To meet them before their mother makes a contract with the parents of the child she will give birth to. To diagnose if they can confront the complicate situation of pregnancy of a child who will disappear.

2. To pay for psychological treatment for the children while pregnancy, and after the baby is transferred for adoption. To help their mother to support them while pregnancy and after birth, and when the baby’s parents vanish with him

**Should pre-adolescent children be given full information regarding possible dangers in a state of emergency?**

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Often children are found in the face of existential threats such as severe illness, a crisis in the family or public threat such as an earthquake alert or violent hostilities.

This question should pre-adolescent children be given full information regarding possible dangers in a state of emergency raises the dilemma whether to inform the child fully or to filter and colour information so as to protect his or her wellbeing. No less pressing is the question what would be “full information” given to children that are six or eleven years old Roberto Benini’s character, in the film Life Is Beautiful (*La vita è bella*, 1997), tells his son, who is with him in the concentration camp, that it is all a game that can be won. The father dies in the war, and the son tells us that the story helped him to survive. While Benini’s stretches the limits of credulity, it seems that the realistic choices of parents to children facing stress are a few:

To conceal information from the child, or to wait till the child raises questions and then to answer with the minimum possible information, or to initiate a discussion with the child according to his age and personality, at the level necessary to deal with information to which the child may be exposed from other sources and with the child’s own desire to know. We will try to cast this noble prescription in terms that fit contemporary bioethics and knowledge on child psychology.

**A Good Death Requires a Process of Engagement with Fear**

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This paper articulates an Aristotelian approach to the correct role of emotions – in particular of fear - in the process of death and dying. The central question that emerges in the paper is: when the object of emotion is the reality of one’s mortality, how should one feel and respond? From an external point of view human beings obviously have a natural lifespan, but one’s sense of one’s own experience does not embody this idea of a natural limit. The true significance of death can only be grasped from a subjective perspective, and from this standpoint one’s death is in most cases viewed as a worst case scenario. Aristotle advocates conceptualising death properly and he claims as death is the end of life that it is the most fearful thing of all. And while one must concede that there may be a certain objective perspective according to which the end of life has little significance, this perspective is not always available to the person in their dying process. The perspective one does have is essentially linked to one’s emotional sensibility. The fear of death is an unavoidable part of this sensibility; and this means that dying and death are fearful. Since, when in the flow of life one cannot work oneself into completely objective knowledge of the significance of death, one cannot eliminate one’s judgment of the fearfulness of death. Nevertheless, one can address the emotion of fear as a whole and allay it.

Contrary to critical opinion, a textual analysis of *De Anima* reveals that Aristotle provides the foundation of his theory of emotion therein, and thus makes it possible to piece together Aristotle’s theory of emotional mechanism. There is a constant relation between the mind and the object in an emotion, and integral to this is an emotional response. The judgment in fear when the object is death is the realisation that one’s life is coming to an end, and this reality is fearful and painful. In *De Anima* Aristotle establishes that emotional responses are intelligent and, therefore, valuable forms of communication. In light of this, *De Anima* illuminates the importance of addressing the emotional dimensions of the human being in the dying process so that one can die well. Narratives of dying taken from literature demonstrate that a *kathartic* development of emotion is natural to the dying process. However, they also provide cases in which the overwhelming fear of death prevented the person from dying well. An attempt to resolve the controversy that surrounds Aristotelian *katharsis*, results in the claim that it is a practical emotional therapy. In an endeavour to provide a plausible proposal for how emotions are to be balanced in the process of dying, I argue that Aristotelian *katharsis* provides a good model for this, as it demonstrates how to engage with the extreme fear of death in a safe context so that it may be overcome and allayed. A good death, therefore, involves an engagement with fear and not the extirpation of fear as the Stoics would have it.

**When patients loose consciousness after requesting an end to life: coma and Alzheimer’s**

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Since physician-assisted dying has become acceptable practice in the Netherlands, changing the nature of debate from confrontation and acceptance into integration, ‘new’ clinical issues have confronted the Dutch with the issue of ethical acceptance or rejection. I intend to focus on two clinical cases where competence has become a central issue in ‘worst case developments’.

The first case concerns patients who have requested an end to their life, where legally required consultations on second opinions have taken place, yet the patients loose consciousness before the intervention can take place and the condition of suffering becomes an issue. I shall describe the policies of the Dutch Royal Medical Society (RDMA) on ‘Euthanasia and Lowered Consciousness’ and its consequences for the practice of euthanasia.

The second case concerns patients suffering from Alzheimer’s who have requested an end to their life, but who are incapable to repeat their requests at the time of the second opinion consultation because of inabilities to communicate on the subject. I shall focus on a recent actual case, describing the position of the law on advance written requests and the confrontation between the latest position paper of the RDMA and the decision of the Euthanasia Review Committees.

**Current Legal Issues Concerning Embryo Research - International and European Union Law Perspective.**

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Rapid progress in genetic engineering and reproductive medicine raised questions about the ability to understand the complexity of life processes and future possibility to apply this knowledge to human beings. Advances of the biomedical sciences opened up the possibility of manipulating early stages of human development. Achievements in the field of medically assisted procreation and genetics are closely followed by concerns about legal implications of new technologies, for they have the potential to change the self-understanding of the humankind.

The most difficult questions arise in regards to the legal status of the human embryo. Increasing knowledge about the nature of the very basic biological processes allows an intervention seeking to modify the human genome. It poses ethical and legal dilemmas for the modern society. New possibilities for the germ-line manipulations can be treated as an increase in freedom that requires a normative regulation, as opposed to empowerment for transformations that depends simply on our preferences and does not require limitation. Developing the legal framework governing the research on human embryo and the use of its results is a necessity. It is crucial to determine to what extent research and medical practice should be the object of legal control and what are the boundaries of these legal limitations. The ultimate objective, however, is that of providing the effective protection of the human rights and dignity of the human being. Consequently, since embryo research and reproductive medicine are matters of great controversy, it is difficult to establish the legal framework on the national level. Because of this reason it is necessary to analyze an international and European approach to the problems of embryo research and reprogenetics.

The aim of the presentation is to identify and analyze the major legal issues concerning embryo research and reprogenetics in order to present solutions provided by international and European Union law. This perspective allows the broader understanding of the problems and can be used in the interdisciplinary debate at international and national levels.

**The Legal Regulation of Beginning and End of Life in Israel: Towards a Comparative Ontology**

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 The paper offers a new comparative framework for analyzing the distinct ways in which Israeli law delineates, and consequently regulates, discrete stages of life and death. The paper identifies four central issues on which Israeli regulation significantly differs (or has differed) from other Western countries: stem-cell research, late abortions, withdrawal of life-sustaining treatment, and defining the moment of death. As many scholars have shown, Israeli law in these cases has been highly influenced by Jewish-Rabbinic law (e.g., Kahn, 2000; Prainsack, 2006; Hashiloni-Dolev, 2007). The paper takes one significant step further and develops a framework for understanding the Jewish-Rabbinic position and, consequently, Israeli regulation. Underlying the Jewish-Rabbinic position is not a commitment to specific *values* (such as the sanctity of life, pro-science and technology, a strive for a healthy body, e.g., Rosner and Bleich, 2000; Sinclair, 2003; Gross and Ravitsky, 2003; Weisberg, 2005), but rather a commitment to a distinct ontology, namely to a distinct way of conceptualizing and depicting *facts* (such as when human life emerges into potential existence, what the stages of pregnancy are, when dying begins and when death ensues). The paper identifies two main ways of conceptualizing the world, or two ontological patterns: a scientific ontology, which views the world through a technological and scientific lens, and a phenomenological ontology, which is grounded in a mundane and unmediated perception of the world. What characterizes Jewish law and Israeli regulation, in contradistinction to many other Western positions, is its grounding in a phenomenological ontology and the various ways in which it distances itself from the scientific and technological worldview while in conjunction accepting science and technology as instrumental means.

**Perceptions of nature, nurture and behaviour: what makes us who we are and what makes people behave the way they do?**

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Trying to separate out nature and nurture as explanations for behaviour, as in classic genetic studies of twins and families, is now said to be both impossible and unproductive. The nature-nurture debate is officially redundant. Geneticists argue that nature and nurture interact to affect behaviour through complex and not yet fully understood ways. An interactive model still seems to assume that nature and nurture, or genes and environments, are separable and, in practice, the debate continues. Research papers by psychologists and geneticists still use the title nature and nurture to consider their influences on everything from obesity, childhood neglect and educational outcomes to psychiatric disorders and sleep.

The aim of this pilot research was to explore ideas on the role of nature and nurture in violent and antisocial behaviour, with particular reference to age differences. Lay understanding of the causes of problem behaviour are relevant both for the public’s acceptance of criminal justice policy, and, because jury members may be asked to consider evidence on common genetic traits said to be associated with violence. These factors have already been cited in criminal trials in USA and Italy.

Until recently, social and environmental theories of crime have been dominant in criminology and in public policy and biological theories have been seen as discredited. However, with increasing research and public interest in genetics more attention has been paid to biological aspects of crime. Media reports have headlined ‘warrior genes’, ‘the aggressive gene’ and the ‘get out of jail free gene’, all referring to levels of monoamine oxidase A (MAOA). Think tanks and ethics groups have considered the ethics and practicalities of genetic testing for behavioural traits. It was therefore hypothesised that public perceptions of the causes of youth crime and antisocial behaviour might reflect an increasing interest in ‘nature’, although popular understandings may never have discarded notions of ‘bad blood’ and ‘pure evil’ .

Given the value put on individualism, autonomy and choice in modern society it was expected that when considering the question ‘who or what made you as you are today?’ respondents would be reluctant to see their own lives as determined by nature/biology/genes but might be more willing to give determinist explanations of other people’s lives and of violent and problem behaviour in others. In fact younger people rejected deterministic understandings of both environment and genes in others while older people were more willing to see environment/nurture as crucial factors in behaviour, particularly in children [in England and Wales the age of criminal responsibility is 10 years]. Older respondents more often expressed the view that environmental factors should be the priority for policy makers and were more likely to see dangers for individuals and society in explanations of behaviour that emphasise nature as causative. *The support of the Economic and Social Research Council (ESRC) is gratefully acknowledged. This work is part of the Research Programme of the ESRC Genomics Network at Cesagen (ESRC Centre for Economic and Social Aspects of Genomics).*

**Lock up Your Patients? Ethical Challenges in the Use of Detention on Tuberculosis Patients**

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While physicians play significant roles in a TB detention program, challenges related to medical ethics and professionalism have not drawn much attention. In the face of the resurgence of TB and the emergence of multidrug-resistant TB, detention has been used in a number of international jurisdictions since the 1990s. In a TB detention program, physicians assist public health in a couple of tasks. First, due to the medical profession’s unique expertise, public health authorities inevitably need physicians’ assist in the design of the detention program. Second, because physicians would likely to note patients with active and infectious TB in the first place, public health authorities may rely on physicians’ alert to warn the risk of the patient to public health and prompt health authorities to evaluate the necessity of imposing detention. Third, physicians may involve in the care of patients under detention. When serving in these positions, what are physicians’ ethical obligations to patients as well as to the general public?

Researches on physicians’ practices related to the use of detention on TB patients have raised critical questions about medical ethics and professionalism. A survey conducted in Ireland found that physicians used the threat of detention as a strategy to obtain TB patients’ compliance. An empirical research on Taiwan’s TB isolation program also reveals that physicians’ decisions to send referrals to nominate their patients for isolation might not be based solely on their judgment of the risk the patient posed; rather, their decisions in initiating the isolation procedure were likely to be influenced by the payment provided by the government. These data suggest that while granting physicians the ability to initiate the detention process is well-intended, it has a tendency to be misused. Hence a national defense against public health risks associated with TB must ensure that health care professionals and the society consider and address the ethical issues that might undermine the legitimacy of the use of personal control measures.

**When Scientists Become Entrepreneurs, What Do the General Public Think About the Conflict of Interest Issues? -- Results of a Public Survey in Taiwan**

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In the past three decades, biomedical research collaborations between industry and academia have been increasing substantially. Not only do many pharmaceutical companies sponsor medical studies, but some researchers also hold significant financial interests in the results of their research. Many biomedical scientists themselves even become investors or founders of the pharmaceutical companies which plan to sell the products they study. This phenomenon without doubt causes conflict of interest to arise more often. When scientists become entrepreneurs, what do the general public think about the possible conflict of interest issues? Would the general public’s trust in the medical research be affected by the researchers’ conflict of interest situations? Would the general public tends to think it is necessary to require the researchers to disclose their financial interests in the informed consent process? Would the conflict of interest affect the public’s willingness to participate in the research conducted by the scientists who are also entrepreneurs? These are empirical questions which cannot be answered by mere ethical theories or reasoning. Therefore, in 2011, the author of this paper collaborated with Academia Sinica using Taiwanese Household Registry Database to conduct a face-to-face survey of a random sample of 1,503 Taiwanese adults. Survey results show that 80.1% of the subjects think that the results of medical studies may be affected by the financial interests held by the researchers, and their willingness to participate in the research conducted by those researchers goes down significantly. Furthermore, 69.9% of the subjects think it is necessary to require those researchers to disclose their financial interests in the informed consent process. The survey results provide evidence for the necessity of regulating conflict of interest situations in order to preserve public trust in medical research.

**The use of worst case scenarios in bioethics**

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Studying worst cases has become a standard in bioethics. Such cases are discussed on professional forums and in medical schools. In my presentation I want to ask if the use of the worst case scenarios is a fruitful approach for scholars and educators and if so, how such cases should be used by scholars or by teachers. For this purpose I will address two questions. First, what is expected from analyses of worst case scenarios as a basis for a theoretical argument and as an instructional tool? Secondly and more fundamentally, how do we know that a given scenario is worst? I will begin with the latter question and argue that in order for a case to count as worst, a normative background is needed which can ground judgments about how bad that scenario is. This background can be provided by a normative theory or by one’s intuitive judgments. In both cases appealing to worst cases in order to formulate proposals for problem solution or for policy making is questionable. If normative theories are to provide guidance for action the study of cases with the intention to support solutions of practical problems is superfluous; if the choice of a case is guided by the case analyst’s moral intuitions the question is what makes such a person’s intuitions reliable. Answering the question about what can be expected from an analysis of worst cases, I will use I. Kant’s distinction between *Beispiel* and *Exempel*. I will argue that if the use of worst cases requires a background normative theory, analyses of such scenarios can be useful at most as illustrations of theoretical claims, not as arguments for proposals. This theoretical placement of the worst case scenarios suggests that analyses of such cases in the classroom can encourage students to analyse difficult problems in order to exercise their judgment which has already been informed by ethical beliefs. Or, if one is sceptical about the very possibility of a normative theory, analyses of worst case scenarios can be seen as negotiations of prospective ethical standards. In either case analyses of worst case scenarios require a specific normative context.

**Doctors' vs. Patients' Autonomy Concept in a Multi-Cultural Environment**

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It is acceptable in the Western society that clinical decisions are carried out in accordance with the patient's wish and approval (the patient's autonomy) as well established in the Israeli law since 1996. The lack of consent regarding this point may cause difficulties in doctor-patient relations. Our study compares the doctors' concept of autonomy and that of hospitalized patients in the unique Western medical center of Be'er Sheva, who come from a variety of cultures- Western and Eastern, immigrants and seniors, Jews and Arabs (mostly of Bedouin tribes).

A non-intervening, prospective questionnaire which included two parts was used. The first part included epidemiological data and doctors' views concerning given statements, whereas the second part used a comparison regarding the doctors' and the patients' judgment of subjects related to the patient's autonomy, the doctor's and the family's authority as seen in clinical cases. A questionnaire was handed out to 105 doctors and to 150 patients, both divided to 3 subgroups: senior Jews, new Russian immigrants and Arabs.

The doctors (5.88 of 7 average) as well as the patients (6.19 average of 7) considered supplying the patient with information concerning his disease of utmost significance and they also expressed their wish to exercise a mutual partnership in the process of making medical decisions regarding the disease and its treatment.

On the other hand, patients feel they do not get the information they require from their doctors and they grade their knowledge of their disease as mediocre, despite the fact that most doctors report that they give their patients detailed information and the majority (about 85%) of all groups express their wish that the patient should be active in planning his treatment and follow-up programs. The majority of both doctors and patients consent that a terminal patient who wishes to terminate his life should not be ventilated even if the doctor and his family members approve of it. Yet, the doctors' consent is more significantly than the patients'.

There is a higher consent among patients that the family of an HIV patient should be informed of the status of his disease despite his objection, compared to the doctors', regardless of cultural or religious differences. There was a significant difference in the attitude towards Autonomy between the Arab patients group and the other two patients groups. The Arabs expressed less interest in their autonomy, especially in their wish to get information about their disease.

The study reveals that doctors approve of the patient's autonomy much more than the patients themselves. Cultural context influences the attitude towards Autonomy and the doctor-patient-family relationship in making clinical decisions. Clinical care givers should be aware of those cultural differences which may exist between patients who were born, raised and educated in the same land and get their medical treatment in the same hospital. Cultural differences may also influence the patients' satisfaction with and response to the treatment, as well as their relation and cooperation with the medical team. Doctors' vs. patients' approach.

**Asymmetry of the attitude to truth-telling to dying patients in Latvia**

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It is difficult nowadays to avoid being shocked after discovering that the virtue of sincerity in physician–patient relationship has been neglected in almost all ethical codes till the middle of the 20-th Century. Such neglect is almost unimaginable after radical changes in medical ethics that have taken place since then, namely, the heavy emphasis on mutual trust, patient’s autonomy and informed decision-making. There seems to be a widespread consensus that all things being equal it is a physician's duty to tell the truth to their patients, even in cases when the news are very bad. This attitude hardly needs any defence nowadays.

However, it does not follow from the above consensus that both involved parties have the same attitude towards truth-telling. A number of empirical studies indicate that in spite of the fact that many physicians assume that patients generally do not want to learn the sad truth about their condition; most patients express the desire to know news even if they are bad. What is paradoxical in the case of physicians is the sort of double standard in their attitude toward truth-telling, i.e., one the one hand, most medical professionals say that they would not speak openly to their patients, on the other hand they themselves wish that they would be told the truth. We call this the asymmetry of the attitude to truth-telling (AATT).

There are reasons to believe that attitudes to truth-telling may vary from society to society. As the tradition of paternalism inherited from soviet health care system has not been completely extinguished yet, we conjecture that AATT characterizes Latvian health care professionals as well. To test this hypothesis we plan to conduct a survey and to compare the attitude to truth telling of medical students to that of practicing physicians. We hope to establish, whether doctors are prone to AATT and how their attitudes differ (if at all) from those of students. Another question we want to address in our paper is what (if anything) should be done with the way of how young doctors are trained. This in turn requires a deeper understanding of AATT itself.

Respect for personal identity and justice in genetic testing and counseling, with a special focus on Italian law

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The paper will concern the topic "Respect for personal identity and justice in genetic testing and counseling, with a special focus on Italian law". The aim is to work out, in the light of a critical analysis of law, the relevance of genetic testing and counseling, with attention to personal identity and justice. Knowledge that may and might be obtained through genetics (as regards pathologies or the risk of occurrence) raise a lot of questions: the acquisition of awareness of possible risks and benefits (as regards the subject or the embryo/foetus), the capacity of acceptance of the answer when there is no possibility of therapy (graduating the right to know and the right not to know), the conflict between the individual interest and the others or society, the possibility of diffusion of information with implications on the intimacy of the subject or on discriminations. In this field informed consent is not sufficient: the social interest needs a balance between private and public sphere and it is necessary to outline the relations between freedom and responsibility. The increasing request of genetic tests tends to show and highlight these problems.

The specific challenges of genetic testing and counseling depend on the type of genetic test that is performed: diagnostic, predictive, susceptibility, pharmacogenetic, carrier, prenatal or preimplantation genetic testing. Also the ethical problems related to genetic counseling depend largely on the kind of test that is at stake. Prenatal and preimplantation counseling might have to deal with the status of the human embryo; carrier counseling will frequently be confronted with the issue of reproductive health; the counseling of children will have to cope with this issue of (lack of ) autonomy. What is common in most forms of genetic counseling and testing is the issue of privacy and confidentiality.

According to this, we want to expose the solutions adopted in Italian law on this issue within the more general principles laid down by the Oviedo Convention on Human Rights and Biomedicine. (The content of the paper is a part of the results obtained in the course of the research “Gen-Etica”, funded by the Italian Ministry for University and Research and done by the Centre for Studies on Biolaw LUMSA – Rome, directed by Prof. Laura Palazzani).

**The methodological problems and the ethical dilemmas in *triage***

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In this paper I argue that triage is a standard procedure in health care. It is just the “usual practice” which is caused by the scarcity or the shortage of resources, on the one hand, and the fluctuating demand, on the other. However, I claim that there are indeed problems and dilemmas caused by this procedure which arise from the criteria that are used in its application under radically varying circumstances.

Conditions that require triage range from extreme cases of natural disasters such as earthquakes, floods, epidemics, a tsunami, a volcano eruption to plain man-made disasters such as wars and terrorist attacks. However, the most common and the most problematic cases are those which are the outcome of shortages that result either from bad planning or from the specific political priorities set in financing the various sectors of health care, e.g., in intensive care, neo-natal care, mental health etc.

The criteria which are used in triage, that is in deciding who is to be treated first or treated at all, are the “conclusions” of informal arguments. The grounds, the reasons, the premises in these arguments derive from the political, the social and the ideological environment existing at the time, the present economic conditions and the available resources. The generally accepted -at the time- moral theory and the medical knowledge concerning the nature of the problem at hand play also a very important role. Lastly, the psychological factor, i.e. the reaction of individual health care providers to critical conditions may alter the designed course of things, the pre-determined policies and apply extraordinary ad hoc measures.

I claim, also, that the methodological problems and the ethical dilemmas arising out of triage are the result of the arguments employed for its justification. The core question which has to be answered is who is going to be treated first or, to use a term that I have employed repeatedly in the past, how and why is one going to be considered a “morally significant addressee of an action”.

**Ethical Considerations of Triage – The IDF Humanitarian Mission to Haiti as a Case Study**

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Natural disasters occurring in populated areas may lead to multi-casualty events and to extensive destruction of infrastructures, including medical facilities. Humanitarian aid delegations sent to disaster zones to provide medical treatment have to cope with, among other pressing needs, the complicated issue of patients' prioritization under circumstances of scarcity of resources. The IDF (Israel Defense Force) humanitarian mission to Haiti (January 2010) is presented as a case study for the various considerations that ought to be included in designing the clinical-ethical policy of a field hospital and for setting priorities between patients.

Two principal questions will be discussed. The first is related to the application of principles of justice: Do the concept of justice and the rules of justice also apply under circumstances of severe scarcity, or are these rules negated, as suggested by David Hume? I argue, contrary to Hume, that the concept of justice and its principles apply even under circumstances of severe scarcity; moreover, the moral obligation to act upon them is not dependent on their advantage to the whole society. The second question deals with the substance of these rules of justice. Here, egalitarian and utilitarian considerations are examined within the context of establishing priorities between patients, and a complex utilitarian account is suggested as a triage model. A critical review of the hospital officers’ decisions at the field hospital in Haiti is examined according to the guidelines of this suggested model.

**Knowing where you come from”: the meaning of genetic relatedness and the right of donor-conceived offspring to know their genetic origins**

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The community of donor-conceived offspring is now coming of age and the voices and concerns of these individuals are coming to the forefront. A growing body of literature is currently emerging, describing their experiences and unique perspectives and fuelling the debate about the right to know one’s genetic origins.

In this paper, I argue that different claims are being made under the umbrella concept of ‘the right to know one’s genetic origins’ in a manner that confounds the debate. To achieve greater conceptual clarity we should distinguish between at least four aspects of this right. Each of these aspects relies on a distinctive understanding of the meaning of ‘genetic relatedness’ and can be addressed by a different policy. The paper delineates these different policies and meanings.

This paper thus describes four aspects of the right: the *medical aspect* which points towards the right to know one’s full medical history and to know medically relevant genetic information about the donor; the *identity aspect* which points towards the right to personal information about the donor as a person (narrative information) that would assist offspring in overcoming identity issues; the *relational aspect* which points towards the right to know the full identity of the donor in order to contact him or her and attempt to establish a relationship; and the *parental disclosure* aspect which relates to the right to know the *truth* about the circumstances of one’s conception as trumping parents’ right to privacy.

I argue that each of these aspects is based on a different understanding of the meaning of *genetic relatedness*. The medical aspect expresses a *narrow* understanding of genetic relatedness as meaningful solely in a *biological* sense; the identity aspect expresses a *broader* understanding of genetic relatedness as having an effect on *personal identity*; the relational aspect expresses an *extensive* understanding of genetic relatedness as justifying an appeal for a *personal relationship*; and the *parental disclosure* aspect expresses the most *far-reaching* understanding of genetic relatedness, seeing it as creating a *connection* powerful enough to justify state intrusion into the family.

Each of these aspects can be addressed by a different policy solution, from disclosure of medical history and genetic information, through disclosure of de-identified personal information, all the way to disclosure of donor identity and to legal enforcement of truth-telling within the family. I therefore argue that these policy options are based on distinctive notions of the role that genetic relatedness should play in the construction of families and in social life. As we expand the scope of the meaning of genetic relatedness, we expand the scope of the right and provide justification for policies that allow it to trump the rights of other parties.

**Ethical decision-making by terminally ill patients**

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End-of-life issues are a standard topic of medical ethics. The vast literature of the last couple of decades however focused most frequently on the moral perspective of *providers* of medical care or assistance to die, and of those *regulating* such interventions or omissions that can hasten death. The moral perspective of *patients*, whose life is primarily affected, is rarely treated. There are several reasons for this. One of them is respect of patients’ autonomy, another is the fact that ‘patient’ is no professional role with a need of a professional ethos. Questions in the providers’ and regulators’ moral perspectives are for instance these: Is it permissible to offer assistance to suicide, if a patient wishes so? Is it acceptable (socially, morally, legally, politically etc.) that certain practices of assisted dying are tolerated? In the mindset underlying this predominant way of constructing the ethical questions, patients’ wishes are treated such as they were givens. The wishes need to be based on relevant ‘information’, and the information process is indeed a topic in medical ethics. But the development of a wish, or the conflicts it encapsulates are rarely looked at. Ultimately, the patients’ wishes remain outside the ethical discussion.

With the advent of empirical methodology and the inclusion of narrative approaches in biomedical ethics, this situation has started to change. The patient is currently (re-)discovered as a moral agent in medicine. We report from a study conducted at three different palliative care settings in Switzerland, with 120 analyzed semi-structured interviews with 30 terminally ill oncology patients, their close relatives and their caregivers. They were focused on the patients’ wishes in regard to their life’s end, and on the ethical implications of the corresponding decisions. To avoid bias, we didn’t narrow the study focus to a wish to hasten death, but interviewed patients with different sorts of ideas towards their dying. The data has been analyzed and interpreted using phenomenological and hermeneutical methodology.

Results show that terminally ill persons can experience and mean quite different things when expressing a wish to die and that deeper knowledge about these differences is indeed ethically relevant. Neither is a wish to die always a wish to hasten death, nor is it always stable, transports continuously the same meaning over the course of time, nor can it be understood outside personal relationships. The data also provide insight into complex, often ambivalent processes of decision-making at the end of life where patients constitute themselves as moral agents and as reflecting ethical subjects. We present several cases and argue that in order to better understand these processes with the view to a patient-centred medical ethics at the end of life, the patients’ voices, their own narratives, need to be heard. A wish to die is not only a wish that one’s life may end at some time and in a certain way, but also an articulation of sense, a reclaim of ethical meaning as a *social and moral* actor in the face the radical contingency of death.

**Introduction to special session**

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Transplantation medicine has special political and ethical implications in situations of political conflict, in particular if donor-recipient relationships cross the borderlines of a conflict. Humanity in such situations can materialize in the gift of life and in the difficult organizational measures that are necessary for the transplantation. All acts involved, however, are inevitably also political acts that in a certain way relate to the conflict. Whether they are intended to or not, they are seen as answers to the conflict. These acts include the gift of tissue or organs, the way stories are told, the media coverage of success and failure, the images used, even the way the events become a topic in the social sciences or ethics.

What can we learn from the experiences in such cases? How can we study these practices fairly? Which effects can the results of the studies have? How can they be used for deepening or for alleviating the conflict? How can we do justice to the people involved, who suffer both from disease, loss, and bereavement? How can medical philosophy and medical ethics discuss these questions? - I will summarize the story of *The Heart of Jenin* as it is told in the film, and briefly develop a rough framework for the ethical and philosophical discussion.

**Integrity and human cloning**

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The birth of Dolly the cloned sheep, in 1997, ignited a worldwide debate about the rightness and wrongness of human reproductive cloning. At present, most scientists agree that cloning poses risks of serious congenital anomalies and premature death to clones. The risks constitute a compelling argument against using the procedure on humans. However, even if, at some future time, the technology became safe and effective, many ethicists, lawyers and policymakers would still argue that it should be banned, because it is contrary to human dignity and integrity.

The aim of my presentation is to analyze the worthiness of moral and legal objection towards human reproductive cloning grounded in the right to integrity. This right is used as a main argument against the technology, in particular, in the Charter of Fundamental Rights of the European Union. Art. 3 of the Charter states that “everyone has the right to respect for his or her physical and mental integrity” (sec.1), and in the fields of medicine and biology the prohibition of the reproductive cloning of human beings must be respected (sec. 2, iv). It is also explicitly enshrined in the paragraph 1 of the WHO Resolution WHA51.10 (Ethical, scientific and social implications of cloning in human health).

Firstly, I will discuss what the right to integrity means and how it relates to the right to (genetic) identity as conceptualized in the existing international regulatory framework concerning new genetic and reprogenetic technologies? Using existing scientific and legal literature, I will create a matrix of the contemporary interpretations (senses) of the concept of human integrity, similar to the working model of human dignity developed by Steven Malby (*Health and Human Rights*, 2002 6(1):102-135). Next, I will test selected elements of human reproductive cloning against each of the integrity concepts contained in the matrix. Finally, I will argue that the concept of human integrity may provide a legitimate rationale for introducing *a priori* a total ban on human reproductive cloning only if the human integrity is understood as a collective human genetic identity and it can be proved that cloning will lead to the erosion of the "genetic heritage of mankind". At the end, I will comment on Norberto Nuno Gomesde Andrade’s criticism of the idea of a collective, static and heritable genetic identity (*Human Genetic Manipulation and the Right to Identity: The Contradictions of Human Rights Law in Regulating the Human Genome,* Script*ed* 2010, vol. 7, no 3: 430-452), and the relation between human dignity and integrity, and practical consequences of the conceptual distinction.

**Sexuality education policies for youth: a value-neutral science-based only approach?**

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Education policies are a keystone to tackle the risks of pregnancy, HIV and sexually transmitted infections among adolescents. However, several authors have criticized the interference of ideology or beliefs in specific interventions applied to sexual education programs. For example, abstinence education is considered non-effective and based on moral and religious beliefs of their proponents. Conversely, there is a growing consensus supporting the so called “comprehensive” sex education programs based mainly supposedly on scientific evidence. A frequent opinion is that using scientific evidence instead of moral debates will help to definitely address sexual risk-taking by teens when public health decisions have to be taken.

The general aim of this paper is to explore why sexuality education policies might neither be neutral or only based on science. The following ideas will be applied to this issue.

The application of biomedical paradigms from evidence-based medicine to public health is necessary but insufficient. It is difficult to extrapolate evidence from clinical trials or meta-analysis into health policy because the contexts of new interventions also have to be taken into account. Science will frequently help policy makers to frame problems but will not necessarily provide a single and “objective” solution. Specific solutions come from a combination of systematic reviews and expert opinions, which involve judgment. The problem with consensus is the elimination of alternatives that may be valuable for the decision-making process of complex problems. A better alternative in health policy might be to articulate the broadest set of plausible interpretations, options and perspectives imagined by the best experts, and in line with scientific evidence, rather than forcing convergence to an allegedly unified idea supposedly only based on science.

It seems logical to think that public health policies should be as neutral as possible and therefore be based on objective measures of harms, benefits and effectiveness. However, facts are relevant to value judgments but they do not settle value disputes on their own. Health promotion policies necessarily include value judgments as well. These judgments relate to the way in which problems are defined and what is taken to be indicators of success. For example, neutrality is naïve in debates about contraception, where some see contraceptives as useful tools for ensuring the safety of sexually active teenagers, while others denounce contraception as licensing unhealthy and immoral behavior. Both perspectives can be confirmed using scientific studies.

Education and health promotion are related to health behaviors. The ethics of changing behaviors depends on which aspect is being targeted. There is a continuum from less to more controversial interventions. Attempts to modify lifestyles related to sexuality raise deep questions because they affect not only health but values that concern the whole person. Parents have different views as to what education is acceptable to influence adolescents’ sexual behavior. Discrimination is possible albeit using apparently neutral practices because persons with a given trait (religious or cultural) can end up disadvantaged with respect to their right to choose a specific education for their children.

**Sunshine on the market – the reasonableness to shed light on medical providers relationship to medical industry**

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Physicians are powerful stakeholders in the medical-industrial complex. Patients owe much of the significant progress made in the diagnosis and treatment of disease to industrial research. It goes without saying that qualified co-operation between providers of medical services, most notably medical practitioners - be it in the field of general medicine or of highly sophisticated sections of tertiary medicine – and pharmaceutical industry is in the best interest of patients. Yet, interest-guided influence exerted by pharmaceutical industry had been shown to have tremendous impact on physicians´ decision-making. Profit-motivated inducement by the pharmaceutical industry may expose patients to considerable risks.

Efforts to shed light on that intricate relationship have not proven successful so far. In the US the sunshine act will come into effect in 2013 ruling every dollar spent for medical doctors to be published in the internet. Yet some authors take the view that the criticism levelled at the pharmaceutical industry as well as the call for transparency of the relationships between physicians and the industry are exaggerated. They hold big pharma being a success. Moreover they argue that undesired consequences of pharma’s activities are allegedly inherent in the underlying market environment shaped by politics. Eventually they think proposals made to control and eliminate pharma’s undesired influence on medical doctors will compromise the most welcome outcome of medical industry’s achievements.

In the debate about the morals of doctors´ relationship to industry it may be helpful to draw on philosophy of politics. In a historical perspective the freedom of the market had been eked out against an authoritarian or a dictatorial state. Now the situation has changed thoroughly. Today individual civil rights and liberties often enough do not have to be defended against encroachments by governmental authorities. Rather, it is incumbent on the state to create rules designed to defend the individual against infringements by overly powerful non-governmental institutions, in our case the medical-industrial complex.

In this paper this historical turn will be reflected. Impacts for the strategies to govern industry’s relationship to medical providers (including the respective institutions) are obvious.

In conclusion, it is the freedom to set limits where they are held to be appropriate which make a free society a distinguished one.

**Masquerading liberal (?) eugenics and hidden agendas: patients in the maze of NRTs**

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Does assisted reproduction merit a different level of protection than natural reproduction? Does funding allow the state greater control over individual freedoms? Israel has a dense maze of bureaucratic, statutory, regulatory and judicial actions that control individuals in their quest of unnatural family building. Purporting to create a favorable and supportive baby making environment it presents traits that upon diligent quest reveal suspect tyrant practices. Public money is spent abundantly on reproductive technology when predetermined criteria are met, while other related areas of medicine remain under much stricter budget constraints. At the same time individuals who do not fit the mold find themselves not only unfunded but unable to acquire status for their newborn where it should be part of his birthright. State authorities exhibit generosity towards reproductive quests of populations behind bars. The ability to control various aspects of reproduction through the perfection of IVF and adjacent medical technology has grown tremendously since its first success in 1978. The possibilities of curbing physical failures of the female and male reproductive tracts enable patients to exert greater control and benefit from a growing arsenal of treatment options in the process of baby making. These choices challenge society with ethical dilemmas as to what should be left to private individual decision making and where the state may intervene, not because it chooses to do so through legislative, judiciary or semi judiciary mechanisms but because such course of action is justified, consistent and streamlined with ethical rights discourse and cultural notions. This paper will explore the gaps in the Israeli maze that regulated NRTs; inconsistently made of lofty High Court constitutional interpretations, tight regulation, abundant funding and judicial and administrative decisions that are tough to reconcile. This paper will further compare the emerging regulatory model and culture to the US liberal models and British model of regulating reproductive technology and raise the question whether state intervention is justifiable in these cases. Looking at the spectrum of reproductive options this paper explores if there is room to adopt different standards for regulation and intervention based on their proximity to natural reproduction or whether in the age of personal autonomy such distinctions are obsolete as long as safety and dignity of all participating individuals is maintained. Applying ethical measures and not plain legal standards we critically examine the justification behind practices and the mandate given to legislative and administrative committees. The paper discusses specific examples where reproductive choices are supported and facilitated or curtailed. It attempts to clarify the hidden meaning and consequences these practices may have on future developments.

**Oncologists’ criteria for end of life decisions in cancer: results from qualitative research**

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*Background*: The care for patients with cancer shows considerable variations with regards to provision and limitation of medical treatment during the last phase of life. Quantitative surveys indicate that the variation can not be explained fully by different preferences on side of patients or medical factors relevant for the individual case. In this qualitative study we explored the experiences and views of oncologists working in Germany and England regarding ethically relevant aspects of decisions about the continuation and limitation of cancer treatment.

*Methods*: Qualitative semi-structured interviews with physicians working in oncology in Germany and England were carried out. Interviews were audio taped and transcribed. Transcripts were coded by identifying major themes of the interviews using constant comparison, in order to examine similarities and differences between oncologists across the whole sample.

*Results*: 17 (Germany) and 12 (England) research interviews were analysed. Interviews varied in length between 27 and 73 minutes. Interviewees from both countries report a number of non-medical variables which may influence professional decisions about the offering or limiting of cancer treatment in advanced cancer. “Physician factors” mentioned by the interviewees encompass personal judgements regarding the priority of treatment goals as well as the amount of clinical experience. In addition “patients’ age and life circumstances” were perceived as influential with regards to treatment decisions in advanced cancer. Multiprofessional team discussions as well as the collection of more evidence regarding the outcomes of different treatment approaches in advanced cancer were cited as strategies to improve treatment decision making in advanced cancer.

*Conclusion*: This study indicates that physicians’ value judgements influence their decisions about offering or limiting cancer treatment in advanced disease. To make explicit value judgements relevant to healthcare professions’ recommendation as well as the collection of evidence relevant to the clinical aspects in advanced cancer may improve ethically and evidence based treatment decisions in advanced cancer.

**Specifying the Precautionary Principle - A four-dimensional Approach**

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Moral philosophy faces severe difficulties as regards answers about how to act under conditions of risk and uncertainty. This especially holds for decisions about options with long-term consequences, more particularly about options which (may) bear negative consequences: in such cases the question arises how ethically justified decisions may be reached.

Regarding conditions under risk, decision theory provides numerous proposals for making the “right” decision, such as Bayes’ rule, the μ-σ-rule and the like. More difficult, however, are decisions under uncertainty, i.e. conditions under which either the identity of the options is not well determined and/or the consequences of at least some option are unknown and/or it is not clear whether information obtained from others, such as experts, can be relied on and/or the values relevant for the decision are not determined with sufficient precision (Hansson 1996).

A well-known proposal for coping with such conditions is applying the so-called precautionary principle (PP). However, to this day no philosophically satisfactory specification of the PP exists. Per Sandin in his article “Dimensions of the Precautionary Principle” (1999) analyzed the most common definitions of the PP and extracted their core elements in order to develop an abstract version of the PP: “If there is (1) a threat, which is (2) uncertain, then (3) some kind of action (4) is mandatory“ (Sandin 1999: 891). Starting from this understanding, it is possible to specify the PP by answering the questions of what are relevant (1) threats and (2) uncertainties that make an application of the PP necessary, as well as what are (3) the right actions with regard to these threats and with (4) what force are they to be mandated.

Regarding (1), I argue that potential threats have to have a certain minimum amount of impact in order to qualify for an application of the PP I then show how such amount of impact may be determined in particular cases. As regards (2), I analyze which kinds of uncertainties have to be dealt with when deciding about whether or not the PP is to be applied. (3), I propose a set of adequate actions that are to be taken depending on the given uncertainties. Finally, I claim (4) that these actions are mandated with a specific strength depending on the expected impact a potential threat as well as on the uncertainties at hand. By doing so, I will present a philosophically satisfactory specification of the PP, which makes it possible to deal with decisions about medical options with long-term consequences in ethically justified ways.

**Born to be a donor. Ethical and anthropological perspectives on ‘savior siblings’**

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The savior sibling is a child who is selected as a result of IVF and PGD/HLA screening and who is born to donate blood stem cells for her sister or brother who suffers from life threatening illnesses of the immune system, such as leukaemia or Fanconi anemia. Being born as a savior child means to serve as a therapeutic tool for the benefit of someone else.

The practice of creating savior siblings presupposes not only the medical technologies such as genetic diagnostic or transplantation technologies but also certain anthropological and ethical views about body sharing, the meaning of life, trans-corporeal gift relationships, and being born under certain conditions. The prenatal history of a donor child includes a selection procedure of corporeal criteria according to the body of its sick sibling and its possible dismissal if it would not have had the HLA-match. Thus, the child is only alive due to certain physical criteria. Furthermore, the medical, social and cultural practice of creating and using a “savior sibling” requires, as I will argue in my paper, a dualist conception of the human: Human bodies are divisible, the person remains untouched.

Creating and using another human’s body as a therapeutic tool means to disassociate the body from the mental and personal integrity. Without such disassociation neither the parents nor society could legitimize such use of savior siblings. This becomes particularly evident, if the transplantation fails. Without such dualistic thinking, we would then need to say that “the child” is a failure, not its tissues. Will the parents who tried to do everything for their sick child be resentful against the little savior child, if it was him or her as a person who didn’t do the job? If it was just the body which didn’t function as therapeutic tool, then at least the child is not to be blamed (subconsciously). The (first) meaning of the savior sibiling’s life is to *have* a therapeutic tool that can be shared and taken as a gift. This has conceptual consequences about the meaning of birth. Normally a birth can be understood as an unconditioned and non-reciprocal giving to a child; but in the case of a created savior sibling the donor child’s birth stands under the condition of having a (life long) corporeal gift for a sick child.

**The trans-planted body as a gift relationship**

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Organ and tissue transplantation presupposes that the human body is taken as a thing, which can be divided, shared, and given to other humans. Organ or tissue transplantation can be life saving; it certainly establishes a very personal body relation which bypasses national borders and political conflicts. Yet transplantation becomes also a cosmopolitical issue: Transplantation practices across political border establish life long gift relationships, which undermines national biopolitics and political conflicts. Yet to convert the gift relationship of transplantation into a peace making policy measure would wrongfully exploit human beings. I will argue that these bodily gift relationships and their operational medical structure may enhance peace but should never be instrumentalized as peace-keeping practice?

**Ethics of Organ Transplantation revisited in view of recent face and composite tissue transplantations in Turkey**

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Organ transplantation is a life-extending and life-saving medical procedure that improves the quality of life. By means of this high medical technology, a whole or partial organ or cells from a deceased or living person can be transplanted into another individual to replace the recipient’s non-functioning organ with the donor’s functioning organ. During the last decades, the science of organ transplantation has developed a great deal by the improvement of transplant outcomes, by the increase of transplantable organs such as kidney, heart, liver, lungs, pancreas that have been replaced successfully in many medical centres over the world (1). Recent remarkable cases of composite tissue allotransplantation for the purpose of reconstructing major portions or all of a number of severe defects, such as the hand and facial deformity have been glimmer of hope for many people lately (2). However, the gap between the demand for organs and the procurement of transplant material still remains wide despite the advances in organ transplantation technology, and organ donation is the key element of this issue which is highly based on ethical and psychosocial factors as well as medical and scientific ones.

Composite tissue allotransplantation is the transplantation of composite tissue for the purpose of reconstructing major portions or all of a number of severe defects, such as the hand and facial deformity (3). Pioneering cases of this revolutionary technique were carried out in France (2005), China (2006) and USA (2007-2009). Clinicians and researchers from Turkey have taken part in the medical teams realizing experimental studies especially in United States just from the beginning (4). This fact provided them with competence and eminence to carry out the procedure in Turkey. The three successive allotransplantations in the foremost medical centres in Turkey at the beginning of 2012 aroused wide attention of the medical and academic circles by the high technology used in these pioneering transplantations. The medical and surgical teams of these highly technological and risky practices are hailed by the public at first by their eminence and zest. However they triggered a broad public debate in Turkey due to the post-operative loss of one of the patients, the sensational news at media breaching confidentiality of the patients and their families, the infringement of the legislation *per se,* consequential cancellation of the transplantation licence in one hospital*.*

The aim of this presentation is to deal with composite tissue and facial transplantation regarding the recent revolutionary examples in Turkey by dragging attention to the ethical challenges of the procedure focusing on the issues of informed consent, confidentiality, balancing benefit and harm, responsibility of the media and the promotion of organ donation without missing to remunerate these major achievements from Turkey in the science of transplantation.

**The proliferation of genetic analyses available to the public**

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In the last 3 years, the availability to the public-at-large at reasonable cost of genetic analysis has surged. These tests help answer questions about genetic origin, parentage, health risks, and carrier state for diseases. At least 3 types of analyses are widely used and prototypic examples are given.

The first was a genomic analysis by a facility entitled DNA Tribes which compares 14--28 genetic markers for a client versus those acquired by global control populations considered stereotypic of that region historically. Thus, cohorts of 100-300 persons among over 1000 populations are analyzed and participants are given a report which identifies a region of the world where their DNA samples are most similar. The results often fail to correlate with familial heritage and the company states that their results determine “deep heritage.” Limitations include the histories given by the control participants, the small sample sizes of some populations, and the inability to test the many population cohorts in the world. Clients may fail to understand a “deep heritage” and the number of markers limits usefulness in paternity or familial testing.

A company from California, 23 and me, provides a combination of marker analysis using several thousand single nucleotide polymorphisms (SNP) and published data on health risks of given SNPs. A large database enables members to compare, identify themselves (optionally) and contact one another. The results do not include diseases where a carrier state (such as Huntington disease) could compromise overall health and some disease risk states include polymorphisms that affect only a fraction of those affected (eg Alzheimer risk by lipoprotein analysis). The advantages are the greatly enlarged number of DNA markers, the associations with health (many need further confirmation, and the misunderstandings by many has caused some states to prohibit usage in medical settings or insurance reimbursements).
A third type of analysis is provided by the largest DNA SNP marker company, Family Tree DNA, from Texas, where the large number of clients and markers tested attracts in particular adoptees who can use designated haplogroup markers to determine the genetic origin of a small segment of their DNA. An option for limited health analyses is also available, but real advantages of large testing services are the ability to locate biologic kin and to confirm suspect relationships.

Can one envision a worst-case scenario amid the wonders of such genomic medicine? The widespread dissemination of genomic data will potentially allow for analysis of predisposition toward future unidentified disease states, determine genetic predilection toward medical syndromes and behavioral states as marker knowledge is increased, and expose one to the potential for future discriminatory practices, affirmative action policies, and arbitrary decision making based on discrete genetic markers. This dissemination thus requires validly informed consent (difficult for nonmedical participants), release from future arbitration, and finally a willingness of participants to embark on the risks associated with disclosure of unknown, future determinants.

**Why treat a worst case scenario?**

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In November, 2011, as a provider to the HIV-infected I was asked to evaluate an AIDS patient sent in from a nursing home. The patient was not ambulatory and the nursing staff asked that I come to a treatment area where bed-bound patients were supervised.

The patient was a 32-year-old Kenyan man with contractures throughout his extremities. He was sent to monitor of antiretroviral therapy. Both his HIV viral load and his level of immune restitution showed good control of infection. Nonetheless, I was struck by the gravity of his underlying disease and thought it might be due to opportunistic infections.

The patient was mute, responded only to severe pain, showed no visible awareness of his surroundings and according to the notes this scenario had been the case for three years at the nursing facility. His vital signs were stable, his contractures were chronic, there was no asymmetry to his neurologic findings, and he showed no acute cardiac, respiratory, or abdominal findings.

It was noted that he emigrated from Kenya in 2001 at age 22. He was HIV-positive on admission into the United States. Because US policy at that time forbade such admission, it was not apparent how he was able to enter the country. Eight years after entry he was involved in a motor vehicle accident and sustained a subarachnoid hemorrhage render ding him permanently aphasic and paraplegic. His care was contracted out to a nursing home in a suburban Houston community where the notes revealed that he never had family or friends visit. I renewed his HIV medications and allowed him to return to what many would consider a near-vegetative existence without significant quality of life.

This case represents the worst of many scenarios in American medicine. Despite a very strident political arena, many number of dedicated social and religious organizations attend needs of the typically hard-working undocumented but these are usually for Latin American immigrants or for patients whose emotional and financial distress are not both catastrophic.

It was my impression that his visits every three months might be his only chance to leave the nursing facility and his limited time at medical visits a significant change in his routine. To us as providers, he represented the type of patient that made one immediately consider “do not resuscitate” orders but at the same time assess our role as providers to patients who undergo in life transitions. These transitions for him included the burdens associated with immigration, a new HIV infection, a near-vegetative state and chronic nursing care in a land remote from his origin where no family or friends exist to help him.

One searches religious background or philosophy systems in how to address such a patient. In the end it is only a willingness to serve a very compromised patient such as this fellow that gives sustenance, purpose, and definition to our work as physicians.

**The Therapeutic Triumph: Making Poor Claims and Offering a Revised Conceptualization to Justify Embryo Selection**

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The paper describes and critically evaluates the medical/social distinction as used in the context of embryo selection through pre-implantation genetic diagnosis (PGD). According to such a distinction, while embryo selection for medical purposes, for example preventing the birth of a child with severe genetic disease, may be ethically justified, screening and selection of embryos for social reasons, such as the implantation of an embryo of specific gender or that carries the gene responsible for intelligence, should not be allowed. The paper challenges the automatic and repeated use of such a distinction in ethical debates concerning PGD. It is argued that existing justifications for the medical/social distinction seem not to support the conclusion that such a distinction should determine in a conclusive way whether embryos should be returned for implantation or misused by genetic parents. The article further analyzes alternative proposals to the medical/social distinction in light of which embryo selection should be ethical and concludes with the author’s own proposal for ethical reasoning in the area of embryo selection. Under such a proposal, any embryo selection that would, on balance, increase the *variety* of potential life plans for the future child from which she will be able to choose is *prima facie* ethically justifiable.

**Who Told You that You Were Naked? Privacy and Whole Genome Sequencing**

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The era of the $1,000 genome is almost a reality, bringing pressing ethical issues to the fore. Over the last two decades, patients and members of the public who have been asked to participate in genetic research, or who have been queried about their attitudes regarding potential clinical applications of their genetic data, have expressed special fears about the privacy of genetic information, a phenomenon sometimes called “genetic exceptionalism.” Critics readily point out that adverse consequences such as discrimination and stigmatization are not unique to genetic data. Arguments to support the claim that genetic information is special have emphasized that these data simultaneously contain information about our present states, our potential futures, and our relatives.

In this paper, I first define privacy as a limit on the access others have to us, generally either regarding one of two spheres: (1) our persons and property, or (2) regarding information about us. I argue that our genomes are not our property in the sense of owning our chromosomes. Nor can genomes be considered as intellectual property that an individual owns. Further, I argue that genomic information is not uniquely sensitive with respect to its potential misuse.

I argue, instead, that part of what makes genomic information seem special is that it uniquely occupies both spheres of privacy simultaneously. To know a person’s genome is both to have knowledge *about* that person and to have knowledge *of* that person. Genomic information, in part, constitutes who and what we are. Genomic information can partly predict our futures, but also represents our futures encoded in us. Genomic information provides an embodied, physical link to our ancestors and our relatives. Genomic information encodes some of our endowments, but also our mutations, our vulnerabilities, and our finitude. While we might soon be able to tinker at the edges, in a general sense our genomes are not chosen but are given to us, like the rest of our bodies. In a metaphorical sense, then, to gaze upon a person’s genome is to see that person “naked,” and such nakedness warrants special protection. It is these qualities regarding genomic information that seem to justify the public’s common view that genetic information is special. Researchers and clinicians who regard such concerns as irrational or ignorant run the risk of alienating potential research subjects and patients and of blunting the potential for great societal and individual good.

**Does germ-line therapy harm to future generations?**

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An ethical reasoning interested in germ-line therapy can not ignore the impact this attempt of treatment has regarding future generations. If one interpretative line could stress the fact that they are voiceless (future generations, some moral philosophers maybe could argue, can not give an informed consent about the altered genome they will receive), on the other hand we must emphasize that the focus here is on the right people should have to inherit an unmodified human gene pool. The implicit thought that substantiates the position we investigate is the following: living persons are not the only field that this reasoning covers: the horizon extends up to embrace what unites individuals through time: the species. So the right above mentioned concerns, at the same time, two subjects. The individual and the species are both, in this light, in the condition to claim what could be called a “natural structure”, which is, indeed, common to the ontogenetic and the phylogenetic level. In other words, the argument we consider, proposing the ban to germ line therapy, is divided in two sectors that, however, remain connected sharing the key point based on the premise that the DNA must remain unaltered - which conducts directly, as noticed before, to the right to ensure the identity (genomic and personal or concerning the species) as unchanged.

Firstly, concerning the individual, an equivalence between the pool of genes and a person’s personal identity could be seen. Herein, the DNA plays a prominent role leading the lives of persons. According to this form of reductionism, the person is conceived merely as the product of his or her genes.

Secondly, what is said about the individual should be referred to the entire species. In other words, the latter has the *germ line* just as individuals have.

We can respond to these positions that 1) seeing a risk in terms of individual freedom linked to born with a modified genetic heritage means adopting a deterministic point of view as regards to the fields of biology and genetic. 2) In the narrow sense, the pool of genes is an abstraction. Because of its internal dynamism, the evolutionary process is unmanageable, therefore modifying the DNA does not mean to orient it removing the freedom of the individual or the unpredictable changes of the species. Thinking in this way implies owning a merely statical conception of the DNA, while its essence, so to speak, is the constant flux.

To conclude, looking from the topic of the ethical problems connected to our moral duties related to future generations, but similar consequences can be traced for example considering the topic of human cloning, our conclusion is that the refusal of applying the engineering technique in attempt to treat genetic disease is not acceptable. A prohibition of this kind consists in an oversimplification because it can be founded only on a deterministic (once referred to individuals) and statical (referred instead to the species) idea of the DNA.

**Is Contraception Health Care? An ethically controversial paradigm shift in US policy and practice with regard to reproductive technologies proposed under the Affordable Health Act.**

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The Patient Care and Affordable Health Care Act (AHA), the most recent attempt at universal health coverage in the US, has accepted and promulgated a paradigm shift proposed by the Institute of Medicine (IOM) with regard to the inclusion of various reproductive health technologies and coverage for such services. A broad spectrum of women’s preventative services slated to go into effect in August 2012 now includes the provision of contraception and sterilization, among other controversial reproductive technologies to be covered by all employers, including faith-based hospitals, colleges, universities and social service agencies who offer health care insurance to employees. Amidst this recent announcement from the US federal government’s department of Health and Human Services came significant backlash from conservative and faith based groups, including the Catholic Church who have until now been exempt from provisions such as these. The fight has been posited as one of *constitutional* *religious liberty* versus *medical* *standard of care* to address women’s reproductive health needs. While some version of this preventative services mandate is on the books in 28 states it did not become widely controversial until the mandate became part of the AHA. Thus in some parts of the US this issue has already been addressed by Catholic Bishops and other faith-based institutions. Moreover, in Catholic countries such as Italy it appears that this particular question has already been adequately resolved. From an international perspective the dilemma in the US seems puzzling.

An accommodation has been put forth by the federal government which is meant to serve as a compromise between faith-based organizations and the federal mandate. The compromise has not been universally accepted. Presently, the Obama Administration is refusing to compromise further and many, though not all, faith based employers are refusing to accept the accommodation as sufficient. This ethical dilemma among religious liberty, delineating a medically appropriate standard of care, and individual conscience has further divided many within US Catholics. In fact, many within the US on both sides are suggesting that this situation can only be decisively resolved by the US Supreme Court.

Additionally, since the announcement, some have sought to shine a light on areas of alleged hypocrisy found within Catholic Health care facilities which presumably weaken claims to conscience of Catholic Hospitals with regard to the contraceptive mandate. Reports which allegedly prove Catholic hospitals are providing other morally illicit reproductive technologies have come to the fore. In light of the upcoming election this issue seems to have taken an even more divisive turn; one whose outcome may be altered by the election in November.

This presentation will begin to address the seemingly confounding circumstances in the US which entrench each side in this ethical debate while other countries have successfully dealt with faith and the use of various reproductive technologies. The presentation will take into consideration Catholic moral teachings on reproductive technologies, secular medical standards of treatment and the on-going political struggle to determine what will be included and excluded from US universal health care initiatives.

**Institutionalizing a Diagnostic System which Pathologizes Typical Human Emotional Responses: Will pharmaceutical companies benefit and will the health of the public bear the burden?**

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The Unites States is poised to adopt the American Psychological Association’s new Diagnostic and Statistical Manual version five (DSM-5) for identifying those with mental health disorders beginning in May 2013. This *improved* diagnostic manual may prove to be overly sensitive, including as deviant those who should be rightly excluded. The adoption of this evolved diagnostic tool will likely give rise both to the inappropriate labeling of individuals as well an increase in prescriptions written for psychotropic medication such as anti-depressants which previously would not have been warranted.

The new DSM-5 has been widely criticized in the US and internationally for pathologizing human emotions, reactions, and behaviors which have until now been seen as normal. The result of which is feared to be substantially greater numbers of individuals being diagnosed with a mental health disorder. Moreover, research shows that the US is more likely than other countries to depend on pharmacological interventions to treat mental health disorders. Almost concurrently, the Patient Care and Affordable Health Act (AHA) will require all mental health providers to utilize the ICD coding system, developed by the World Health Organization (WHO) and more widely accepted across the globe for diagnosing mental health disabilities and other physical disorders. The ICD system and the DSM system have, however, developed in parallel ways across the years with each influencing the development and use of the other.

Given the preference in the US to prescribe psychotropic medication in response to diagnosis, it should be asked both who stands to reap the greatest gain from this new diagnostic system and who stands to reap the gain of continuing with parallel diagnostic tools. It appears that an increase in the number of people diagnosed with mental health disorders previously deemed non-pathological will facilitate an increase in those eligible for treatment with a variety of psychotropic medications thereby benefitting the pharmaceutical industry perhaps to the detriment of the individual seemingly inappropriately labeled and treated based upon an overly inclusive diagnostic system.

This presentation will identify the ethically troubling proposed changes and will address how the changes proposed in the DSM-5 will hyper- pathologize normal emotions such as grief which may cause harm to those newly diagnosed by being labeled with a mental health disorder and undergoing unnecessary interventions while simultaneously benefitting the already robust pharmaceutical industry currently disproportionately relied upon for the relief of symptoms in the US. Given the historical evidence of parallel evolution of the DSM and the ICD tools, the international community should attend to the outcome of this ethically concerning dilemma as the potential for international ramifications may include a greater international dependence on the pharmaceutical industry to ameliorate mental health disorders. This is a situation of worst case diagnostics with potentially far reaching consequences.

**The Role of Pandemic Plans in Ethical Preparedness & Resilience**

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Pandemic preparedness planning, as an instance of general disaster planning and response activities, focuses on how particular institutions and officials will seek to manage serious viral outbreaks within their community. One prominent form of planning in anticipation of the emergence of a pandemic threat are pandemic preparedness plans created by national governments. In addition to outlining the medical and legal guidelines/processes to be followed during a pandemic, a large number of plans also include ethical considerations to be considered in informing policy and action. This inclusion reveals a recognition that not only will ethical considerations be of central relevance to pandemic planning, but that inclusion of ethical guidance will contribute to a more effective response and promote greater resilience. In addition to national pandemic plans, supranational and international documents, such as the WHO’s *Addressing Ethical Issues in Pandemic Influenza Planning* and EUR-OPA Major Hazards Agreement *Ethical Principles on Disaster Risk Reduction and People’s Resilience to Disaster* also exist with the same objectives. Unfortunately, there is little or no evidence that these plans/documents contribute to ethical preparedness or resilience, nor even that public officials have or will make use of the ethical principles listed to guide their conduct or decision-making processes. It is argue that, at least in their current form, most pandemic plans cannot be said to be properly ethically action-guiding, nor should they be thought to provide some metric by which the level or quality of ethical preparedness or prospective resilience within a community can be assessed. The mere inclusion of ethical considerations within these plans or documents is not a sufficient indicator of ethical preparedness or resilience. A great deal more work – in terms of research, development and evaluation – must be done to better understand and integrate ethical guidance within pandemic planning specifically and risk and disaster management generally.

**Personalised medicine: Priority setting and** **opportunity costs at an international scale**

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Personalised medicine currently gains considerable attention and evokes a multitude of hopes in modern medicine. The identification of genetic markers enables more precise diagnoses, targeted therapy and more specific statements about the personal prognosis. Often used as synonym for future medicine, personalised medicine promises to be better, cheaper and more "personal" than current medicine.

However, big achievements in basic genetic research do not mean necessarily better personal treatment for the majority of patients in clinical medicine. It is more likely that future clinical success in targeted therapies will be limited to subgroups of patients, e.g. patients with a specific breast cancer, only. In contrast, a considerable part of patients will have no personal benefit at all.

In fact so called “personalised medicine” is a research and economy driven adventure governed by global stake holder e.g. pharmaceutical and biotechnology companies. Since economically independent and publically funded research is missing widely, these private interest groups are setting the research agenda following their commercial interests. In this context and with the record of current cost development of new cancer drugs in targeted therapies the promise of cost saving and cheaper health lacks any evidence.

Furthermore “personalised medicine” is associated with ethical problems like priority setting and opportunity costs in solidarity based public health care systems, social and global justice as well as ethical questions of autonomy and of beneficence of patients. It is an issue of debate how societies and public health systems may influence the development of the research agenda regarding the priorities for future health care. We argue that in case of a lack of critical reflection on the current focus on “personalised medicine” public health care will be confronted with modern, highly specific and expensive diagnostics and treatments, which will serve subgroups of patients only. At the same time research in other fields of clinical medicine, comparative effectiveness research and public health, which could serve more than some subgroups of patients, remain underfunded.

**The Two Arms of Openness: Responsibility and Creativity in Medical Professionalism**

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The ethos of medical practice is historically expressed in the language of excellences (i.e. virtue), especially those that inspire responsibility (on behalf of the professional) and trust (on behalf of the public); contemporary milestone documents of medical professionalism, such as the “Medical Professionalism Charter” and the ACGME (The American Council for Graduate Medical Education) underscore a commitment to constant improvement in medical research, education and the standard of care. Thus the concepts of innovation and excellence are invoked in tandem. However, medical innovation also presents potential harm to patients. However, innovation presents some challenges to medical ethics. The image of the brilliant physician applying her genius by the bedside is as appalling as it is appealing. Experimenting with novel treatments (pharmaceutical, surgical or other) always entails some unknown risk to the patient even when ethical boundaries are observed – and medical history is littered with examples when these boundaries were violated.

Thus, physicians need to negotiate these seemingly conflicting demands: to act in the best interest of the particular patient, and to promote the profession as a whole. Specifically, situations of extreme risk and limited resources – such as disaster relief – may push or even require physicians to improvise in their practice. In this paper we attempt to explicate this dilemma by developing a joint account of creativity and responsibility. We argue that this conceptualization of creativity should count among the second-order virtues of medical professionalisms, which organize first-order virtues such as compassion and skill.

Our argument follows psychologist Robert Sternberg's conceptualization of creativity, according to which creativity is a composite of (1) the perception of reality as changeable, (2) the ability to discern potentials for change, and (3) the ability to identify which of these potential is valuable. Creativity thus defined and responsibility it its conceptualization as a meta-virtue both require the somewhat paradoxical traits of embeddedness in reality on the one hand and willingness to alter it on the other, suggesting a conceptual link between the two. Responsibility may serve in a guiding role, directing creativity towards valuable alternatives.

**Ethical challenges of a prolonged hunger-strike**

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Recently a young man, detained in prison without trial under security regulations, was admitted to hospital after 52 days of hunger strike. He agreed to cooperate only after an external doctor representing a human rights organization was allowed to accompany his treatment. As his condition became increasingly critical he progressively accepted treatment with infusions containing only minerals, then thiamine supplementation, and finally, intravenous glucose. When partial parenteral nutrition (PPN) was offered he consented on condition that this be formally defined as essential treatment, and not a break of the hunger strike. Deliberation on this issue involved Physicians for Human Rights - Israel, the International Committee of the Red Cross, the hospital ethics committee, and international advisors. A document was presented to the patient stating that in the circumstances of his particular case, PPN would be deemed to be essential medical treatment and not a breach of his hunger strike. Nonetheless the patient refused treatment pending a High Court of Justice hearing of his appeal against detention. A few hours later, the court ruled to shorten his detention, and he promptly ended his hunger strike, on the 66th day. Among the many ethical issues arising from this case, we will focus on some salient points - Creation of a therapeutic space in the context of detention without trial; Defining and protecting confidentiality in the chaotic nexus of a hospital bed surrounded by prison warders, medical students, lawyers, human rights activists, politicians, the media, the prison medical service representative, and family members, with varying degrees of access to information and to the patient; Empathy and patient advocacy in the face of the dramatic political asymmetries and theological differences between patient and doctor (a West Bank Palestinian spokesman for the Islamic Jihad, and an orthodox Israeli Jew); Simultaneous cooperation with both the hospital staff and the prison medical service; Manipulation of the body and its medical care in the service of political goals, and how moral agency for such action is distributed between the patient, the doctor, and the State; The epistemological quandary of the possibility of providing a medical as opposed to a political definition of what constitutes breaking a hunger strike. The status of PPN in the treatment of hunger strikers – a topic that seems not to have been discussed previously in the literature.

**Transnational Pharmaceutical Corporations’ Moral and Legal Human Rights Responsibilities for Access to Medicines**

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For decades the lack of access to needed and affordable medicines has unduly burdened developing countries worldwide. To highlight the acute need for international assistance in support of the sick’s and poor’s medical plight, in addition to the state’s human rights obligations to fulfill the right to access medicines, scholars have manifested increasingly visible alarm over the activities and enormous power of transnational pharmaceutical corporations (TNPCs). However, requiring TNPCs to assume human rights responsibilities in relation to access to medicines is replete with conceptual difficulties because human rights law was traditionally thought to apply almost exclusively to states, and, only in limited cases, to individuals and corporations. In effect, as far as the right to access medicines is concerned, TNPCs have only moral responsibilities to facilitate pharmaceutical accessibility, and their normal business operations and voluntary philanthropy form the main corporate contribution to the preservation of this right. However, it is misleading to impose only moral responsibilities categorized in the “can” (rather than “ought to”) dimension on TNPCs to improve access to medicines regardless of heterogeneous contents of the right to access medicines. In addition, corporate philanthropy cannot provide a consistent response to right-to-access-medicines violations, especially in pandemics and disasters. Therefore, TNPCs’ human rights responsibilities for access to medicines should not all be subject to the criterion of “morality”, but should be differentiated and prioritized based on the contents of the right to access medicines. Based on the biomedical health model and Norman Daniels’ theory of just health care, in which “function” and “opportunity” hold a precise meaning thus are readily measurable, I propose that: (1) TNPCs “ought to” fulfill the right to access medicines (soft-law human rights responsibilities) when and only when these medicines are necessary for restoring or maintaining “minimal health” (including life-saving) without which an individual cannot be a free and equal member of society and the right loses its significance, and (2) TNPCs “can” voluntarily fulfill the right to access medicines (moral human rights responsibilities) for common or insignificant physical and mental dysfunctions or for pain-killing that go beyond the level of “minimal health”. Two reasons prompt this differentiating hierarchy of TNPCs’ human rights responsibilities. *First*, since life-saving medicines are closely related to the right to life that is not only non-derogable but also holds jus cogens status, and since international precedent reveals that corporate liability for jus cogens violations should be contemplated under international law, it is important to impose soft-law (rather than moral) responsibilities to promote access to these medicines on TNPCs. *Second*, since minimal health defines an individual’s essential capacity to function as a free and equal member of society and to obtain fair shares of the normal range of opportunity to pursue his or her own good ends of life, TNPCs, with increasing power and capacity to affect healthcare policies and/or pharmaceutical patent policies, “ought to” enhance access to minimal-health-maintaining medicines, especially in light of the inability of public sector to protect the right to access medicines in developing countries.

**Disclosure of HIV+ Status to Patient’s Family: Law, Ethics, and Public Health**

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Due to the discriminative nature of AIDS, keeping HIV+ patients confidentiality is of critical importance and should be strictly followed as a prima facie ethical obligation by all health care providers. However, when the patient tested HIV+ is incompetent, can and should the result be disclosed to his family? There are various ethical, legal and public health controversies concerning this question. First, as a surrogate decision-maker, patient family might need to know the exact diagnosis to make a sensible health care decision for the patient’s best interest. Moreover, in the case of patient incompetence, the family becomes the only information source for the public health officer to trace the potential infector for AIDS control. In addition, HIV+ patient family might have an independent right to know the origin of infection so that they can exercise their legal right to sue the person/institution that negligently or intentionally transmitted HIV to the patient. Despite of all these seemingly legitimate reasons, it should be acknowledged that disclosure of AIDS diagnosis to an incompetent patient family may cause serious harm to another HIV+ patient’s confidentiality.

This paper starts with a real case in Taiwan where a HIV+ person (hereinafter Mr. P) was harassed, blackmailed, and criminally accused by his boyfriend’s father, whose 22-year-old son was died of AIDS-related brain tumor. After being told by his son’s doctor of the cause of the disease, the heart-broken father carefully investigated and finally located Mr. P a possible infector. Without precaution, the local health officer confirmed Mr. P a HIV+ carrier, and then his nightmare began. Raged and grieved, the father takes for granted that his son was killed by Mr. P’s intentionally transmission of HIV virus. In addition to civil claim and criminal charges against Mr. P, this angry father made Mr. P’s HIV+ and gay status public to his parents, co-workers, and employer, and all these cause huge pain and suffering for Mr. P. Though Mr. P did contract HIV earlier than his dead partner, a genetic test revealed that each of their HIV viruses was from different sources.

Who should be responsible for Mr. P’s miserable treatment? Is it ethical for the treating doctor to disclose AIDS diagnosis to the father at the first place when the brain tumor was in end stage and knowing AIDS does not help in making medical decision but in applying for financial support? Can the AIDS reporting system be more sensible to infector’s privacy protection? How to assure that a HIV+ person take good steps to prevent his sexual partner from affected? This paper will examine all these issues in detail and try to propose an ethical guideline to incorporate HIV+ patient right to confidentiality with public interest of AIDS control.

**Human Cloning: Between a crime against Humanity and the Common Heritage of Mankind**

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On 2005, the general assembly of the United Nations adopted its Declaration on Human Reproductive Cloning (United Nations Declaration on Human Cloning, GA Res. 59/280, Annex (March 8, 2005)). The declaration followed two decades of lively discussion among ethicists in the medical and scientific community regarding the warranted regulation of HRC. Throughout this time, while numerous scholars strongly opposed the very idea of HRC, other thinkers supported its conduct or even encouraged scientific endeavor in this area. People from both camps, however, agree on two things. The first is the need for an appropriate mechanism for regulation of HRC. The second is the imperative role international law should play in the legal regime of HRC. The goal of this paper is to critically examine the methodology and tools of International Law that have been suggested for the regulation of HRC, both contextually and in terms of the likelihood for successful enforcement. In particular, we will discuss and analyze three models. According to Annas and his colleagues, HRC is a crime against humanity (Annas GJ, Andrews LB, Rosario MI (2002) Protecting the Endangered Human: Toward an international treaty Prohibiting Cloning and inheritable alterations, American Journal of Law and Medicine, 28:151-178). As such, it should be outlawed by an international treaty. Luban, in response, states that cloning is a crime against humanity only if we regard genetic uniqueness a defining aspect of humanity (Luban, David (2004), A Theory of Crimes against Humanity, Yale J. Int'l L. 29: 85-167). However, because cloning does not violate aspects of humanness pertaining to our political nature as required in international legal instruments it could not be considered as a crime against humanity. Finally, we will offer an alternative view of the practice of HRC, relying on the doctrine of Duty Based Common Heritage and its application to the human genome (Ossorio PN (2007) The Human Genome as Common Heritage: Common Sense or Legal Nonsense? The Journal of Law, Medicine & Ethics, 35(3): 425-439).

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