Abstract book

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ABSTRACTS

Justice & medical ethics: Parallell session I

Subsistence emissions in healthcare

Joshua Parker

How can healthcare systems reconcile reducing their emissions with providing healthcare benefits that have historically relied on emissions? To what extent should the goals of healthcare place a limit on mitigation burdens for healthcare systems? One way to answer this question is through a distinction between luxury and subsistence emissions as this helps demarcate permissible emissions from those liable to mitigation burdens.

Subsistence emissions are those necessary to secure a decent life and so, in as much as healthcare appears necessary to secure a decent life, this distinction holds much intuitive appeal. There is however a need to understand which healthcare emissions are subsistence by clarifying the nature of this concept. I take up this task in this paper.

I argue that subsistence emissions should understood as a sufficientarian concept. As such, subsistence emissions set two thresholds for healthcare systems in order to demarcate permissible emissions. The first threshold is familiar to sufficientarians and is the threshold of enough health. Those below this threshold have healthcare needs that should be prioritised over those above the threshold. The sufficientarian threshold refers to a vertical threshold, the second threshold is a horizontal threshold. This threshold provides the scope of possible interventions that represent legitimate claims to medical resources. I discuss the nature of these thresholds. In addition, I consider where to set these thresholds arguing that they should be sensitive to planetary boundaries as well as more local healthcare needs. Finally the paper deals with allocation above and below the sufficientarian threshold.

Does scarcity in health resources change ethical obligations? On the idea of normative tipping points

Ulrik Kihlbom

Some bioethicists argue that a specific scarcity of health resources, e.g., a shortage of ventilators at an intensive care clinic, creates a “tipping point” after which allocation of resources is to be made by different ethical norms or values than before this point was reached. The common suggestion seems to be that rationing after the tipping point should be based on maximizing utility, rather than on human rights, equality or prioritizing the worst off.

In this talk I will, after some preliminary notes on the concept of a tipping point, critically explore this idea and argue that a) it is has some merits and b) the most reasonable interpretation is that it is a meta-normative idea that sits better with particularism or disunitarianism than with universalistic theories such as utilitarianism, right theory, egalitarianism, or deontology.

Underestimation of pain in women as an example of epistemic injustice rooted in gender biases

Viola Tognoni

Underestimation and underdiagnosis of patients’ pain is a problem that involves many healthcare systems worldwide. Among the categories of people more affected, the case of women is particularly relevant. In this paper, I investigate the phenomenon of underestimation – and consequent undertreatment – of pain in women and show how this is rooted in a series of gender biases that affect the medical and caregiving practice. I illustrate the relevance and consequences of such biases by looking at two experiments on pain’s estimation and at the clinical case of Chronic Pelvic Pain. Based on this analysis, I then explore the problem from a philosophical standpoint, focusing on the specific type of injustice that occurs against female patients. Considering the work of philosopher Miranda Fricker, I explain why the phenomenon of underestimation of pain in women can be seen as an empirical case of epistemic injustice within the context of healthcare. Every time a woman is not believed in her description of pain, what happens is that she is not fully trusted as a knower, or epistemic subject. This is the case whether a) because the healthcare provider bears a prejudice or stereotypical conception of the category of people the patient belongs to (women), or b) because the patient lacks the linguistic tools to express her condition. These two scenarios not only perfectly mirror the definition of epistemic injustice given by Fricker, but also embody in many in many respects the two possible forms epistemic

injustice is articulated in, namely testimonial and hermeneutical injustice.

Finding a Balanced and Justified Approach to Withdrawing and Withholding Treatments in Healthcare Rationing

Liam Strand, Lars Sandman

In this study, we explore the ethical implications of withdrawing and withholding treatments within the context of healthcare rationing. We analyse both the moment of the reimbursement decision and the decision to grant early access to treatment pending reimbursement eligibility. Our preliminary findings indicate similar consequences between post-reimbursement withdrawal and withholding, and concerns regarding resource efficiency and patient equality by not withdrawing post-reimbursement. However, withdrawal may encroach upon patient freedoms. Additionally, providing early access to treatments raises concerns regarding health inequalities, undermines reimbursement assessment, and risks inefficient resource allocation if treatments prove cost-ineffective. However, the decision to grant early access may be warranted if the likelihood of reimbursement is high and the assessment period is brief. Overall, our study underscores the importance of distinct analyses for withholding and withdrawing treatments in specific case.

Priority to the worse off and diagnostic measures

Erik Gustavsson, Niklas Juth

The extent to which a condition is severe constitutes an important part of several approaches to health care priority setting. For example, the Netherlands, Norway, Sweden, and the UK are all countries with explicit criteria for priority setting that apply severity as one of their considerations. However, these criteria are mainly applied to treatments rather than diagnostic measures. When the criterion of severity is applied to treatments, it is often applied as follows: the more severe a condition is that a treatment targets, the higher cost can be accepted per health improvement. For example, a health care system may be willing to spend twice as much for a comparable treatment effect on a condition that is considered to be very severe compared to a condition that is considered to be merely moderately severe. However, to apply this approach to diagnostic measures gives raise to several challenges. We shall focus on three of them. First, a conventional method for priority setting is the systematic ranking of different health conditions and their treatments. The matching of a specific treatment to a specific condition is helpful since it allows for considering several relevant aspects for priority setting such as severity of disease and the patient's capacity to benefit from the intervention as well as its degree of cost-effectiveness. Consequently, the conventional method allows decision-makers to decide whether one group rather than some other group should be prioritized. However, diagnostic measures will often target larger segments of patients – segments that cut across the typical patient group in the conventional model. How should severity be guiding priority setting with regard to such products? Second, medical technology may often constitute a part of a diagnostic procedure. If a specific product targets a very severe condition, should each product that constitute a part of the diagnostics be judged as targeting a very severe condition? Or should the severity be downplayed with regard to how large part of the diagnostic procedure it constitutes? Third, diagnostic measures, such as whole genome sequencing, will often generate secondary findings. Several guidelines for opportunistic screening (using e.g. whole genome sequencing) suggest that identifying or diagnosing secondary indications should only be done when it is proportional to do so, i.e., when the potential benefits outweigh potential risks with identifying the condition in question. To determine if the criterion of proportionality is fulfilled, some limit of sufficient severity has to be settled: how severe should a condition be in order for it to be worthwhile to identify as a secondary finding? So, considerations of severity enter the determination on what to do opportunistic screening for from the beginning, but it remains unclear how it should make a difference more specifically.

Empirical ethics: Parallell session I

Views and experiences on enabling physician-assisted suicide: Interviews with Swedish physicians

Filip Jonsson, Manne Sjöstrand, Ulrik Kihlbom

The only legal option for Swedish patients who desire physician-assisted suicide (PAS) is to travel to Switzerland. To access PAS there, patients need medical certificates from their physicians. However, Swedish healthcare law and professional ethical guidelines lack clear directives on how physicians should handle such requests, which may place physicians in perceived ethical and professional dilemmas. How physicians reason about their professional involvement in writing such certificates has previously not been studied in a Swedish context. The aim of this study was to describe and explore physicians' opinions and reasoning when confronted with requests for PAS or requests to enable PAS in Switzerland.

12 semi-structured interviews with physicians from different specialties (oncology, neurology, palliative care, psychiatry, general practice, internal medicine) were conducted, transcribed, and analyzed using qualitative content analysis.

Informants reasoned they had a professional responsibility to assess their patient's needs, including addressing fears, optimizing care, and existential aspects. Informants were willing to write certificates to enable PAS. Simultaneously, many informants argued that performing PAS in Sweden should not be part of their professional role. Some informants were more positively inclined but wished for a due process that would help correctly select patients.

Views on professional responsibilities and what to assess in a patient who expresses a wish for PAS seem central to the physicians' reasoning. While informants seem willing to enable PAS in some situations, that does not automatically extend to a positive attitude toward legalization of PAS in Sweden.

Perceptions of lifestyle-related risk communication in patients with cancer– a qualitative interview study

Åsa Grauman, Erica Sundell, Jennifer Viberg Johansson, Nina Cavalli-Björkman, Jessica Nihlén Fahlquist, Mariann Hedström

Informing people about their risk can have negative consequences, such as inflicting unnecessary worry and stigma on the individual. This study aims to explore how patients with breast- and colorectal cancer perceive and experience risk communication, and the increased focus on lifestyle behaviours as the cause of cancer.

Semi-structured interviews were conducted with 23 Swedish patients age 34-79 years. The collected data were analysed with theoretical thematic analysis.

Five themes with additional sub-themes were identified: Thoughts and feelings of the cause of cancer, Moralizing messages and negative encounters, A need to act, Trading uncertain risks with living a good life, and Societal benefits of risk communication. The cause of cancer is closely related to the possibility to act to prevent relapses. This could be one reason why participants both experienced feelings of self-blame and hope for the future. The participants expressed that it is important for, their wellbeing, to be able to act. The participants requested both information and support from healthcare providers. Therefore, risk information entails both feelings of self-blame and hope for the future. Being able to act is important for patients' wellbeing. Patients request both information and support from health care providers.

Patients, including those with healthy lifestyles, may find moralistic risk information offensive. Balancing information involves providing transparent, evidence-based information while considering individual and social contexts, avoiding stigmatization and blame, and supplementing information with support.

Patient and transplant staff experiences with liver transplantation and the transplant benefit score: ethical analysis of a qualitative interview project

Jamie Webb

The Transplant Benefit Score (TBS) was introduced in the UK in March 2018 as a method of allocating livers for transplantation. The TBS is both far more algorithmically complex than the previous and offers less clinician autonomy in allocation decisions, with livers being matched to particular patients from a national database. The TBS has been the subject of recent media attention, with pieces from BBC News and The Financial Times questioning its fairness and comprehensibility. This research project – which interviewed 29 patients and transplant staff on their perspectives on the TBS – is the

first piece of in-depth qualitative research on the topic. This paper explores its findings, relating the experiences of patients and staff to key ethical themes of high stakes resource allocation, including consent, contestability, trust, the clinical role, and staff-patient relationships. For patients, what were they told about TBS? How far does its algorithmic complexity affect patient comprehension and understanding of how their prioritization decisions are made, and what impact does this have on patients? Were patients empowered if they (or their clinicians) disagreed with their prioritisation score? And for staff, how do they explain TBS to patients? How has algorithmically determined allocation changed how they consider their role and their relationship with patients? And how, if at all, do both patients and staff gain and maintain trust in the system? The findings of this project will be of interest to anyone considering the growing role of complex algorithmic systems in healthcare, including nascent machine learning technologies.

Value Conflicts and Ethical Challenges Among Dietitians when Prescribing Oral Nutritional Supplements

Susanna Pohjola, Åsa Grauman, Anna T. Höglund, Elin Lövestam, Margaretha Nydahl & Evelina Liljeberg

Dietitians have a significant role in prescribing oral nutritional supplements (ONS), when food-first strategies are insufficient. However, negotiating conflicting values and challenges in the decision-making process can induce ethical distress among dietitians, emphasizing the necessity for ethical analysis in the matter.

The study aimed to explore value conflicts and ethical challenges among dietitians in ONS prescription.

Semi-structured interviews were conducted with 13 dietitians across Sweden from October 2019 to April 2020, spanning primary care and hospital settings. Data were recorded, transcribed, and analyzed using systematic text condensation (STC).

Three overarching themes were identified throughout the analysis: Patient participation, Structural prerequisites, and Interprofessional collaboration and responsibilities. For instance, the findings indicate value conflicts, such as balancing honoring patient wishes with professional judgement. Moreover, the dietitians related ethical challenges to patients' prerequisites such as their diagnosis, economic status and geographical location. Additionally, it was observed that other healthcare professionals tended to promise ONS prescriptions to patients before the dietitian completed their assessment, potentially leading to unmet patient expectations. This practice might also undermine the authority and professional judgement of the dietitian.

Several value conflicts and ethical challenges were identified in ONS prescription, emphasizing the need for ethical competence to balance those based on biomedical principles. This would promote patient well-being and rights, facilitate fairer assessments and decisions and possibly reduce ethical stress among dietitians.

The Ethical Reasoning of Parents Who Continue Pregnancy After a Prenatal Diagnosis of Down's Syndrome: a Qualitative Interview Study.

A S Aylwin, C A McCoy

Previously, two independent fields of inquiry have existed: bioethicists discussing the ethics of prenatal testing and termination of foetuses likely to be disabled and empirical social science research which examines the experience of parents who decided to continue a pregnancy with a child with a serious disability, such as Down's Syndrome. Uniquely, this qualitative interview study aims to compare the ethical arguments of professional bioethicists who write on the topics of prenatal testing, disability and abortion with the moral reasoning, lived experiences and thoughts of 15 individually interviewed parents who decided to continue pregnancy after a prenatal diagnosis or high chance test result of Down's Syndrome. We describe two ways bioethicists' and parents' views align: (a) the benefits of life as counterbalances for potential harm; and (b) safeguarding children's 'essential interests' while maximising their welfare. Additionally, the fields of inquiry differ regarding: (c) the condition of continued right to life of a foetus; (d) the belief that all human lives are worth continuing, irrespective of experiential quality; (e) the harm to prospective parents' dependents; and (f) the risk of violating the duties of justice. Separately, bioethicists consider the societal impact of potential genetic disorder transmission, whilst parents experience the prospective regret of abortion and formation of a parental bond during pregnancy. This research seeks to inform the ethics of reproductive technologies, including prenatal testing, by providing greater context about how parents consider the ethical decision-making process of continuing pregnancy and how this could diverge from the ethical arguments of bioethicists.

Equitable digital health interventions through cultural adaptions: Current practice and challenges

Vasileios Nittas

Digital health interventions (DHIs) promise equitable care access. Yet, despite broad access to the internet/smartphones, racial/ethnic minorities benefit less from DHIs. That is because current DHIs fail to capture the cultural norms of minority populations, leaving them excluded. One way to change that is through cultural adaptations, which is the tailoring of existing DHIs to a group's cultural identity.

We conducted semi-structured expert interviews (n=15) and aimed to capture current practice, challenges, and recommendations. Participants were identified through publications and snowball sampling. We used iterative thematic analysis, guided by a deductively and inductively derived codebook.

We identified three themes: (1) pre-adaptation, (2) adaptation process, and (3) challenges.

Two questions emerged as important before the start of a cultural adaptation: (1) why must an existing DHI be adapted, and (2) how is culture defined? We found that involving prospective users (of the focal cultural group) in the adaptation process is the gold standard. Good user involvement is (a) timely, (b) iterative, and (c) continuous, complemented by feedback from experts/stakeholders, specifically in technology. Responses revealed three adaptation areas, including language (tone, narrative, complexity), lived experience, and technology (design, functions). The adaptation team must be multi-professional and culturally competent. We identified five DHI-relevant challenges, including (1) technology, (2) uncertainty, (3) user involvement, (4) communication, and (5) sustainability.

Cultural adaptations of DHIs may improve access for underserved communities. Our work describes current practice and underlines existing gaps, and technology-specific challenges. We call for the development of DHI-specific adaptation frameworks.

Neuroethics: Parllell session II

Why should neuroethics strive for crossing cultural boundaries

Michele Farisco

There is a growing discussion about the statute of neuroethics as a scientific discipline (Farisco et al. 2018; Johnson and Rommelfanger 2018). There are at least two main reasons why this debate is still open: (1) the discipline is quite young, so there is still the need for clarifying both its methodology and content; (2) since neuroethics is conceived as an interface between academic research and different societal stakeholders, a number of different factors impact the identity of neuroethics (including its methodology and content). Cultural diversity is among the most impactful factors shaping neuroethics, both as a scientific discipline and as a social enterprise.

In my talk, I will present two models of culture and neuroethics for investigating their mutual relation, with a specific focus on cultural diversity as recently analyzed in the book Neuroethics and Cultural Diversity, which I edited.

The quest of neuroprotection through neurorights. Disciplinary and practical challenges

Manuel Guerrero

Human rights are dynamic. They synthesize collective efforts to get states to respect and protect every person's dignity and take positive action to facilitate a life worth living. At different times in history, changes have been demanded to give adequate protection and recognition to these rights and limit the power that positions some groups in a situation of vulnerability or weakness compared to others. Thus, there are times when the guarantees that protect rights are extended to new social groups. The idea of the minimums that allow a dignified life and the current possibilities of well-being also varies. The recent inclusion of the notion of neuroprotection into the Chilean Constitution, accompanied by the formulation of a Neuroprotection Bill (Law No. 21.383, Senate of the Republic of Chile n.d.b), can be read as new steps within this historical dynamics of human rights, in this case as a pioneering local effort to regulate neurotechnology development and applications. This chapter describes such attempts focusing on the Chilean human rights debate around these new brain-related issues.

Discourse Ethics on the Background of Mirror Neuron Theory as a Possible Contribution to Bioethical Principles

Jan Šteffl

The paper first briefly introduces discourse ethics and the theory of communicative action. These are two systems with which Jürgen Habermas contributed to the discussion. Although these are not a priori bioethical principles, I will try to outline that they have their scope and general applicability. It will be based on the theory of mirror neurons, which has been known to us since the 90s and on which modern theories regarding empathy are based. Here is the main meaning of the paper, which will try to explain empathy as a basic challenge and disposition of each individual on the one hand, and to use the above-mentioned ethical theories on the other. To show how rules can be established when dealing with others and in which ways social norms can be shaped. The contribution will therefore be multidisciplinary, specifically in the field of contemporary neurology and neuropsychology, with an overlap into what we can call postmodern ethics and will also show approaches that have often been applied in our countries and which are based on a deep tradition of phenomenology. The paper will therefore not repeat already known principles, but its goal will be to present principles that can serve as general ethical (or human) pillars and substantiate this goal with the perspectives of mirror neurons and the perspective of discourse ethics.

Neurotechnologies and Human Rights Protection

Jonathan Andrew, Timo Istace

The ongoing development of neurotechnologies presents impacts, opportunities and challenges for the promotion and protection of all human rights. Whilst advances in neurotechnology can provide for improved human health through their innovation and implementation, the continued development of certain applications may also however pose both ethical and legal concerns, including in human rights terms.

Research into these implications, currently at a relatively early stage, has already uncovered distinct concerns — these implications include direct externalities (for example, the violation of the rights to privacy and freedom from discrimination) and indirect externalities (possible spill overs for social cohesion, equality, and tolerance toward other persons). Further study is vital to examine in a coherent, holistic, inclusive, and comprehensive manner how neurotechnologies might best be exploited so as to deliver maximum benefit to humanity, supporting human progress and development for all whilst also protecting human rights. Far greater reflection and examination is needed of the potential impacts of the human rights of vulnerable individuals and groups including children, the elderly, persons living in poverty, people with disabilities, and Indigenous Peoples.

The presentation will present the research findings conducted in connection with Resolution 51/3 of the UN Human Rights Council and invite discussion during the ensuing Q&A session as to the salience of the existing international treaties protecting human rights in regulating current and emerging neurotechnologies; asking whether indeed specific, additional legislation or mechanisms might be required to protect fundamental rights, taking particular account the risks faced by vulnerable groups and minorities.

Research ethics – Africa: Parallell session II

Research participants' perspectives on compensation for participation in biomedical research in cancer patients at uganda cancer institute

Ruth Nagawa

Compensation is an ethical endeavor in appreciation for the time and effort that individuals provide as participants in research. Uganda has no guidelines for the compensation of research participants leaving the issues of undue inducement, inadequate compensation, and tendencies toward participant exploitation. This study aimed to analyze the views of research participants to add their voices to measures to ensure ethical compensation of research participants in biomedical research.

The objectives were to explore research participants' views on compensation, determine their preferred compensation method, and explore the factors that influence their choice of compensation method.

This was a qualitative cross-sectional study that employed in-depth interviews with 22 women aged 20 to 49 at the Uganda Cancer Institute in 2019. Data was analyzed thematically and managed using Nvivo 12.

Participants regarded compensation from different perspectives: a motivation for them to participate in research as it would cover their incurred costs and a token of appreciation for their participation. The majority felt that the amount offered was inadequate considering the time input, inconveniences, and travel expenses but would go ahead to participate even if it was not offered because the study would provide health benefits to them and future patients. The suggested forms of compensation were: monetary, non-monetary, and a combination of both.

Findings suggest that compensation is a continuous endeavor where participants ought to feel valued for their contribution to the research relationship. Deliberate ways of participant compensation would go a long way in protecting participants from harm and exploitation in biomedical interventions.

Ethical aspects of broad consent and the future use of biological samples and data collected in biomedical research in Malawi and South Africa

Francis Masiye

Recent developments in biomedical research have introduced new ethical challenges in obtaining informed consent in low- and middle-income settings. More specifically, there are controversies about the use of broad consent for the collection of biological samples and data for future use. However, few studies have explored key stakeholders' views on preferred informed consent models and future use of biological samples in sub-Saharan Africa. Therefore, this study conducted in Malawi and South Africa aimed to understand key stakeholders' views on four different informed consent models (specific, broad, tiered and blanket consent), and their opinions on future use of biological samples and data in biomedical research with the goal of potentially influencing current policies on these in the two countries.

This qualitative study used in-depth interviews (IDIs) and focus group discussions (FGDs) with key stakeholders including REC members, research funders, policymakers, CAB members, patients' advocacy group members and research participants in biomedical research in both Malawi and South Africa. Thirty-four IDIs and 6 FGDs were conducted in Cape Town in South Africa, and in Blantyre and Lilongwe in Malawi.

Most participants preferred broad consent and tiered consent to specific consent in the collection of biological samples and data for future research, and also recommended their indefinite storage and future use. Majority of the participants felt that donors of biological samples are the rightful owners of their samples and have the right to make decisions about what happens to the samples. Some participants strongly preferred specific consent to other consent models used in biomedical research. Few participants did not have any preferences and opted for any consent model which provides adequate information about the proposed research. Only very few participants preferred blanket consent to other consent models in both countries.

To the best of our knowledge, this is the first study in sub-Saharan Africa to explore key stakeholder opinions on the four informed consent models and on future use of

biological samples in health research. The study has attempted to help fill gaps in literature on key stakeholder views on informed consent models for future use of biological samples in both Malawi and South Africa. We hope that these findings will inform current debates on acceptable consent models and future use of biological samples in both Malawi and South Africa. The findings may also inform current policies on storage and future use of biological samples especially in Malawi. Finally, we recommend further research on stakeholder perspectives on collection, storage, and future use of biological samples in other sub-Saharan countries since the findings from this study cannot be generalized to other countries in the region.

Enhancing Ethical Standards in Scientific Research Publications: Insights from Nigerian Medical Colleges

Timothy O. Ajayi, Komolafe D Ayokunle, Daniel T Olaniyan, Lawal Azeez

This research explores the ethical standards governing scientific research publications, focusing on perspectives from Nigerian Medical Colleges. The study critically reviews key ethical considerations such as authorship, conflict of interest, duplicate publication, disclosure of competing financial interests, data access, and confidentiality. By addressing these issues, the paper aims to guide authors in ensuring the ethical integrity of manuscripts submitted for reviews and subsequent publication.

The study proposes actionable measures to address publication misconduct committed by stakeholders in the research article publishing profession. These recommendations are designed to elevate the quality of scientific research within Nigerian Medical Colleges by establishing best practices for journal article publications and addressing potential research misconducts that may arise during the publication process.

Recognizing publication ethics as essential for the acceptance of journal articles, the paper underscores the significance of ethical standards in safeguarding against research misconduct. The research emphasizes the importance of adhering to well-researched policies that delineate the responsibilities of both researchers (authors) and publishers, thereby promoting research integrity. Drawing on Morie's (2013) framework, the study encompasses various aspects of publication ethics, including authorship, plagiarism, text-recycling, self-citation, duplicate publication, disclosure of competing financial interests, confidentiality, and issues related to guest/gift and ghost authorship. This research contributes to the ongoing discourse on publication ethics, providing practical insights and recommendations tailored to the unique context of Nigerian Medical Colleges. Ultimately, the paper aims to foster a culture of ethical research conduct, thereby enhancing the credibility and quality of scientific research in the academic community.

AI, ethics & law: Parallell session III

Transparency demands and the justified usage of AI in healthcare

Björn Lundgren

Transparency and related concepts, such as explainability, are amongst the most common requirement in AI ethical guidelines. Moreover, they are often considered necessary for justified usage of AI in healthcare. Here I argue that the demands for transparency are too strong, I specify what is necessary for justified usage of AI in medicine and conclude that current system can already satisfy those demands.

My arguments will be based on the following type of considerations. First, it is generally recognized that there is a double-standard when it comes to transparency demands for automated decision-making systems relative to the transparency demands we have for human decision-making. Second, many AI systems in healthcare are not used to replace human decision-making but function more like other medical devices and tools. Third, AI systems are already proven successful in areas such as cancer diagnoses, showing that there is cost to restricting usage of these systems.

Can ChatGPT Do Medical Ethics?

Lukas J. Meier

ChatGPT is already being used for various tasks, including writing code, enhancing search engines, translating texts, personalising customer experiences, and even for cre¬ative endeavours. But how good is it at doing medical ethics? To establish this, I con¬fronted the chatbot with classic moral dilemmas and analysed its responses.

In interpreting the cases, ChatGPT relied on Beauchamp and Childress' four prima-facie

principles: beneficence, non-maleficence, respect for patient autonomy, and justice. While the chatbot's output appears admirable at first sight, it is worth taking a closer look: ChatGPT not only misses the point when applying the principle of non-maleficence; its responses also fail, in several places, to honour patient autonomy – a flaw that should be taken seriously if large language models are to be employed in the clinic or even just in ethics education. In my talk, I will therefore subject ChatGPT's replies to detailed scrutiny, point out where it went astray, and evaluate whether using large language models for solving dilemmas in medical ethics would be a good idea.

How to ensure that AI medical devices in precision medicine achieve the required quality of care in Sweden?

Sarah de Heer

My research examines how to ensure quality of care in Sweden as regards a specific AI medical device, namely an automated decision-making system, which predicts an outcome based on machine learning or deep learning, in precision medicine. To be placed on the market, a medical device is to pass the conformity assessment procedure under the Medical Devices Regulation or the In Vitro Diagnostics Regulation (Medical Devices Regulations). This procedure leads to the affixation of the CE marking and prompts a strong legal assumption. Medical devices bearing this marking are deemed to comply with all requirements of the Medical Devices Regulations – including those verifying the quality of care, which is a pillar under the right to health. Depending on the medical device's classification, third parties, 'Notified Bodies', are tasked with this procedure.

My research examines to which extent the current Medical Devices Regulation can guarantee the required quality of care in automated decision-making system in precision medicine, while using the doctrinal method and scrutinising legislation, case law, and literature. While Notified Bodies should guarantee the quality of care, my research argues the contrary due to a lack of adequate access to information. This hampers the verification of the quality of care, and thereby the right to health. AI exacerbates verifying the quality of care due to their inherent characteristics, including the ability to evolve without any human involvement. The aim is to identify the obstacles, proposing recommendations may be developed in further research.

Autonomy & coercion: Parallell session III

Suicide-preventive compulsory admission is not a proportionate measure - time for clinicians to recognise the associated risks

Antoinette Lundahl

Suicide is considered a global public health issue and compulsory admission is a commonly used measure to prevent suicide. However, the practice has been criticised since several studies indicate that the measure lacks empirical support and may even increase suicide risk by itself. In this normative study, I investigate whether the practice has enough empirical support to be considered proportionate. To that end, arguments supporting compulsory admission as a suicide-preventive measure for most suicidal patients are scrutinized. The ethical point of departure is that the expected benefits of compulsory admission should outweigh the potential harms of the measure to be proportionate and defensible. It is concluded that, for most suicidal patients, suicide-preventive compulsory admission cannot be presumed to be a proportionate measure. To be so, the expected medical benefits of the measure should be greater than the potential increase in suicide risk and other harms that compulsory admission could entail. Instead of using compulsory admission as a suicide-preventive measure, extra safety measures may be needed during and after compulsory admission to prevent the risk of hospitalisation-induced suicide.

Patient autonomy under coercive conditions: GPs' and migrant women's moral dilemmas

Sawitri Saharso, Saartje Tack, Laurine Blonk

Coercive conditions related to traditional gender roles and unequal power relations can lead to health problems for women, such as depression, for which they may seek the help of a general practitioner (GP). Patient autonomy is central to GPs' decision-making processes on medical interventions in such situations. Theories on the value of patient autonomy focus primarily on impediments to autonomy capacities (e.g. children, psychiatry, dementia). We argue, however, that such a framework is ill-suited for understanding how women negotiate coercive conditions and

offers little guidance for GPs in their dilemmas around respecting patient autonomy under coercive conditions.

In this paper, we build on the 'empirical' turn in bioethics that seeks to improve context-sensitivity, by presenting the findings of our study into GPs' and migrant women's moral perspectives and dilemmas regarding medical intervention related to coercive conditions. We draw on 39 interviews and 9 focus groups with migrant women living under coercive conditions, and 19 interviews and 7 focus groups with GPs. Inspired by feminist and decolonial theory, our analysis shows that while context constrains women's autonomy, women also exercise autonomy within constraints. In theorising autonomy under constrained conditions, we aim to move beyond the dichotomy between autonomy and coercion, and discuss how our perspective on autonomy can provide useful tools for more gender and culturally sensitive care for patients living under coercive conditions.

Vaccination, purpose, and permissibility

Lisa Forsberg

There is a widespread assumption that vaccination should be voluntary (at least by default), that is, that recipients' consent is required ('the consent assumption'). In this paper, I argue against the consent assumption, by considering an argument made in respect of interventions employing medical means for the purposes of crime-prevention—the argument from purpose—according to which the acceptance of a consent requirement in respect of such interventions assumes that they are best understood as primarily medical interventions whose permissibility should be assessed against the standards of medical ethics, rather than interventions whose permissibility should be assessed against the standards of criminal justice ethics. This assumption relies on a mismatch between purpose and permissibility norms that requires justification. I consider a parallel argument, according to which the acceptance of a consent requirement in respect of vaccination assumes that vaccination is best understood as a primarily medical intervention whose permissibility should be assessed against the standards of medical ethics, rather than an intervention whose permissibility should be assessed against the standards of public health ethics for public protective interventions. I consider three objections: (i) that a consent requirement remains in place, regardless of purpose, because vaccination interferes with our bodies; (ii) that the argument from purpose mischaracterises the nature and purpose of vaccination; and (iii) that the standards of public health ethics are not permissive of nonconsensual interventions. I argue that none of these objections are insurmountable, and that nonconsensual vaccination is much more easily justified than often thought.

More varied and principled understandings of autonomy in health law

Isra Black

In influential work (at least in English health law), John Coggon has argued that three mutually incompatible conceptions of autonomy may be in play—and inconsistently applied—when an individual refuses medical treatment and their mental (and thus legal) capacity is challenged. Current desire autonomy, according to which an individual is, other things equal, autonomous if their choice reflects their first-order desires. Best desire autonomy, on which the agent's choice must reflect their second-order desires. And ideal desire autonomy, for which an individual's choice must accord with some 'objective' reasons for action in order to qualify as autonomous.

I consider (and gently challenge) Coggon's explanatory framework for mental capacity law. I argue that we ought to understand mental capacity law as taking an interest in the instrumental rationality of an agent's decisions. Three observations seem to follow from this conclusion. First, Coggon's view pays too little attention to the distinction between formal and substantive conceptions of autonomy. Indeed, it may neglect the formal dimension of autonomy by apparently positing three rival substantive accounts. Second, if capacity is a matter of instrumental rationality, any of Coggon's three accounts may be applicable in similar cases without inconsistency. For mental capacity would depend on each particular agent's conception of the good. Third, Coggon's three accounts seem too narrowly to specify the concepts of prudence (or goodness) that agents may employ in their medical decision-making.

Relationship theory & practice in medical ethics: Parallell session IV

Philosophical-conceptual competences and their contribution to medical ethics – Examples based on the conflict between autonomy and well-being

Anna Hirsch

How can we deal with conflicts between autonomy and well-being in patient care in an ethically appropriate way? Clinical ethics counsellors are confronted with this central question of medical ethics on a regular basis. In clinical ethics and medical ethics in general, the four-principle approach is often used to address this question. However, it only provides a rough framework for weighing up conflicting duties. It is criticised for its wide scope of interpretation and the resulting lack of action orientation. As I see it, one reason for these shortcomings is the underdetermination of the concepts on which the four principles are based on, including autonomy and well-being.

Analysing concepts and examining theories more thoroughly are genuinely philosophical competences. I will present these competences in more detail using a selection of papers on autonomy and well-being. In doing so, I illustrate how philosophers add value when dealing with practical questions of medical ethics. I will discuss the methods and the specific expertise of the authors. Based on this, I will draw conclusions for clinical ethics: Which of the philosophical competences can support clinical ethics counselling? What difficulties need to be considered? In my presentation, I will dispel the prejudice that philosophy is removed from 'reality' and loses itself in marginal debates. I will argue that the philosophical analysis of concepts and theories makes an important contribution not only to academic medical ethics, but also to practical challenges in patient care. Philosophical competences, I suggest, are an indispensable part of medical ethics.

50 years of killing and letting die: On the limits of philosophical bioethics

Joona Räsänen

In 1975, The New England Journal of Medicine published James Rachels' article 'Active and Passive Euthanasia'. The argumentative method Rachels introduced, the Bare Difference Argument (also known as the Contrast Strategy), became one of the most widely used tools in ethical reasoning. As I will argue, the argument, however, fails to show active euthanasia being morally permissible. It fails because Rachels takes the intuitions from the case where letting die is morally impermissible and applies the intuitions to cases where letting die is morally permissible – a neglected mistake made also by Michael Tooley. While it is possible to create though-experiments that are more analogous to euthanasia, in this respect, than Rachel's cases, they too are disanalogous to euthanasia with some of the relevant features. Creating the perfect analogy, however, would be a mistake also. Such a case would be too analogous; people would simply be divided on what kind of moral intuitions they would have. The problem thus highlights a methodological limit in philosophical bioethics and raises questions related to the roles of philosophical ethicists in the context of assisted dying and beyond.

Teaching the beneficence principle

Joar Björk, Thomas Hartvigsson

Beauchamp's and Childress's Principles of biomedical ethics (PBE) is arguably the most influential work in contemporary medical ethics. In particular, the principles presented in their book have become the main framework for teaching medical ethics to healthcare professionals. Perhaps the greatest appeal of the Principles-approach is that it offers a straightforward and easily applicable framework that still manages to capture much of the complexities inherent in clinical decision-making. Despite the initial promise of clarity, teachers and learners (predominantly healthcare professionals) often struggle with understanding and applying the framework in a clear and consistent manner.

In our contribution we will focus on the beneficence principle, and outline five different problems of application we have encountered in teaching medical ethics. We will show how these can be traced to ambiguities in Beauchamp's and Childress's own work as well as to complexities in the application of the principles to ethical challenges in the clinic. We will propose a coherent interpretation of the principle which is suitable for teaching medical ethics to novice and intermediate level learners within a relatively short time frame. We propose that our interpretation manages to preserve PBE's initial promise of clarity and easy applicability, while being ethically sound and theoretically consistent.

To be or not to be – Ethics support staff's perceptions of patient and parent participation in clinical ethics support services in Nordic paediatric oncology

Isabelle Billstein, Cecilia Bartholdson, Anders Castor, Bert Molewijk, Pernilla Pergert

There is a growing support for patient and parent participation (PPP) in Clinical Ethics Support Services (CESS). Despite this, participation is increasing slowly due to complexity of execution. Thus, we need further understanding in how to create forums where patients' and next of kins' ethical concerns and perspectives are highlighted. The aim was to examine perceptions of, and factors affecting PPP in CESS. In this qualitative study, Nordic ethics support staff (N=27) working with CESS in or in connection with paediatric oncology were invited to focus group interviews (n=6). Most participants were healthcare professionals without former experience of PPP in CESS. Data was analysed with inductive content analysis. Ethics support staff perceived that PPP in CESS could bring several benefits, for example influencing understanding and trust and conflicts. However, fear of harming overshadowed potential advantages and included concerns regarding influencing of conflicts and creating dilemmas of decision-making participation. Strategies to avoid causing harm were expressed on different levels of contexts like: organizational (challenging the ambiguity of ethics and CESS, preparing and debriefing, creating a safe environment), relational (balancing of care relationship, protecting of child-parent-relationship) and individual (assessment of child participation, assessment of parent participation, assessment of healthcare professionals' exposure). PPP in CESS can be seen as an ethical dilemma of its own and one could question if healthcare is too paternalistic concerning PPP. In cases where PPP in CESS may be considered, it is important to apply strategies to reduce the risks of causing participant harm.1

A pluralistic use of moral theories in bioethics, illustrated with cases on moral distress

Anne-Marie Søndergaard Christensen

Understanding the relation between moral philosophy and bioethics is complicated. Since the solidification of bioethics and related disciplines there has been extensive discussions about methodological questions of the relation between theories and concepts from moral philosophy and the cases and issues of interest in bioethics, resulting in the development of various approaches, top-down, bottom-up, principlism, casuistry etc. More recently, bioethics have seen intensive debate about the relationship between input from moral philosophy and empirical studies of ethics, currently solidifying in approaches such as critical ethics, particularism, integrated empirical ethics etc.

As part of this development, bioethics have effectively left behind the idea that theories from moral philosophy authoritatively establish and prescribe what theoretical frameworks are to be applied in bioethics. Still, there have been very little discussion about how then to understand the choice and roles of moral theories in bioethics. In this paper, I want to contribute to this discussion. First, I will argue for a pluralistic understanding of the field of bioethics. Second, based on recent work on moral theories, I will argue for an understanding of moral theories as representation of the various normative grammars at play in the field of bioethics. This allows for the use of a plurality of moral theories, describing a plurality of moral grammars, in the analysis of bioethical issues. To illustrate my proposal, I will discuss cases from research on moral distress.

The currency of severity

Adam Ehlert

When making priority setting decisions in health care, it is becoming more common to rely on some notion of severity, where conditions (or patients with conditions) that are judged more severe will, all else being equal, be given higher priority. There has been a discussion whether the "currency" of this severity should be understood in objective or subjective terms. It can be argued that even though one condition can affect two different people in the same way (from a pathological point of view), that does not necessarily mean that it is equally severe. For instance, if a devoted piano player develops a condition affecting the mobility of her fingers, it might be possible that this condition makes her worse off than the same condition would make someone else. Two interesting questions follow: 1) what, if anything, is it that make her worse off? 2) in what way does this matter for priority setting. Using some illustrating examples, I will examine these questions and argue that the currency of severity has to involve at least one subjective component (in addition to some objective components). I will suggest that one of the things that can make someone worse off than another person suffering from the same condition is how much the condition deprives that person of the ability to perform meaningful activities.

Current issues in medical ethics: Parallell session IV

Risk, Polycrisis, and Top Hazards

Lars Lindblom, Erik Gustavsson, Lars Kåreklint

Risk management policies for disaster planning are under redevelopment. Recently, the European Parliament put forth the Critical Entities Resilience Directive (CER), which states that "...each Member State should have in place a strategy for enhancing the resilience of critical entities." (Europe Parliament 2022, p. 167). A crucial part of such a strategy is to have that "an overarching framework that addresses the resilience of critical entities in respect of all hazards, whether natural or man-made, accidental or intentional" (p. 165). This will affect policy in crisis and disaster management in healthcare. Such redevelopment may be necessary due to what has become known as polycrisis. Roughly, this term aims to describe a state of affairs where there are several large risks at once, which either correlate or causally interact, and where "the whole is even more overwhelming than the sum of the parts." (Tooze 2022) However, the kind of focus on an All Hazards Approach found in CER has been criticized as being inefficient. Instead, Bodas et al (2020) has proposed what they call the Top Hazard Approach. On this approach, one first makes a ranking of risks in order of magnitude, and then focuses all resources on handling the top-ranking risk. In this presentation, we will argue that the Top Hazard Approach should not be accepted as an approach risk management. We provide three reasons for this view. First, in a situation of polycrisis, it seems ill advised to pick out one of the particular crises and solely focus efforts on it. Given causal interactions between risks, it may result in misleading rankings of risks. Secondly, there are well known efficiency problems with the kind of lexical orderings of policy implementation that is inherent to the Top Hazard Approach. For example, the top hazard may take all our resources, at the same time as we could bring about a larger net of risk reduction by handling lower-level risk. Finally, a ranking of risks in order of magnitude is distinct from a list that ranks options for risk management in terms of how well they help us to avoid or mitigate risk.

The Living Document

Camilla Lyckblad

The increasing practice of granting patients – and in pediatric care, also parents – access to digital medical records has significant implications for the autonomy of medical staff in their documentation practices. This qualitative interview study aims to understand the impact of digital medical record access on healthcare professionals and guardians of child psychiatry patients with medical documentation insight. Clinician informants in the study have described the medical record as similar to a sentient presence in the room with them and the patient, lingering on their shoulder during documentation. This feeling of the medical record, a document once kept close to heart in the private hands of doctors, now experienced as a malleable being watching them, is a striking historical shift. The research aims to deepen comprehension of information behavior in clinical contexts, where the medical record is viewed as an entity that both listens and influences. This exploration may shed light on the complex dynamics of trust within clinical environments, where patients, parents, and doctors might selectively disclose or withhold information in order to safeguard themselves. The increasing power of the transparent medical record raises the question of whether this authority will ultimately undermine documentation, potentially leading to professionals refraining from documenting certain things altogether. This questions the nature of truth in transparent documents. Consequently, it also raises inquiries about the implications for care and the practice of medicine that emerge from this process.

A Critical Analysis of the Ethics of Critical Care Resource allocation during the initial dominant surges of the COVID-19 Pandemic in a major UK teaching hospital

Andrew Webb

The dominant waves of the COVID-19 pandemic led to unprecedented demands on critical care resource allocation, for an already oversubscribed system in the UK.

Following the reported experiences of Italian Hospitals at the onset of the pandemic, University Hospital Southampton rapidly made provisions to increase intensive care bed capacity within the hospital and also providing an additional 'clean' Hyperacute Surgical unit in the adjacent Spire Private Hospital.

A clinical and managerial team undertook daily adjudication meetings to maximise capacity based on Utilitarian Ethical principles of resource allocation, to ensure that all of the demands of local and national emergency referrals for COVID patients were catered for, along with the requirement of all other emergency and cancer patients.

A comparative analysis of critical care resource allocation will be presented based on utilitarian principles of allocation for the first two COVID waves compared with the preceding year.

Despite the two waves of COVID admissions to ITU, the capacity for emergency and cancer patients was maintained at comparative levels to previous years. The patient group that experienced significant cancellations were the cardiac surgery patients directly reflecting the numbers of COVID admissions.

Utilitarian principles of resource allocation can allow for emergency crisis management, although we would argue that deontological based planning is required to prepare the UK for the next pandemic.

Development of a public health ethics framework for lighting

Mirko Ancillotti, Deborah Mascalzoni

Excessive and improper lighting poses ecological concerns due to the impact on fauna and flora and its contribution to global electricity consumption and greenhouse gas emissions. For human health, scientific evidence suggests that it causes sleep disorders and may severely affect an array of biological functions and processes, including cancer, metabolic, cardiovascular, and neurodegenerative disorders.

Lighting concerns — often framed as light pollution — are primarily conceived as an environmental issue and discussed in terms of environmental ethics. This entails considering the effects of excessive lighting on human health as a facet of a broader problem and balancing human interests against those of other entities, as they would be intertwined with concerns over animal and environmental harm. This only marginally accounts for the magnitude and potential severity of the problem for human health.

We advocate for public health and public health ethics as key arenas for addressing lighting-related concerns along with those already existing. As public health takes the population perspective, its ethical dimension often implies a dilemma between individuals or groups and the larger community benefit. Furthermore, coordinating various actors is frequently crucial for achieving positive public health outcomes. These characteristics involve the need for public health activities to be continuously evaluated and justified from an ethical standpoint and to assist policy-makers and administrators with purpose-built ethical means to inform their decisions. We aim to map ethical principles relevant to lighting initiatives to provide a framework of reference to support policy and decision-making.

Considering the ethics of ‘live tissue training’ in trauma surgery

C Swain, R Rickard, K Karlgren, G Helgesson

‘Live tissue training’, is a type of simulation which uses an anaesthetised live animal as a human patient substitute for the practice of surgical skills, notably in the speciality of major trauma. Although simulator technologies have developed significantly for inclusion in many areas of surgical education, it is contested that training to manage traumatic injuries requires a model that can bleed and has a dynamic circulation.

This presentation explores the values at stake regarding live tissue training in the context of trauma. We consider the utilitarian and deontological positions of the topic and describe the pro- and contra- arguments, evidenced in the published literature, relating to this type of simulation training.

We argue that a discussion of the relative benefits of different simulation models for trauma training is most obviously relevant to a consequentialist outlook. When considering if live tissue training can be justified to any extent, we present criteria for ethical evaluation:

1. There must be educational benefits from using live animals
2. The benefits of live tissue training cannot be achieved as well or better by replacing live animals with the use of other simulation models
3. The added value of the educational benefits from using live animals, compared to other available simulation models, must outweigh the (added) ethical cost

Our considered conclusion is that justification is challenging and must be considered on a case-by-case basis – educational benefit gained from a live animal compared to the best alternative simulator must be greater than the clear ethical downside.

Being a living organ donor: A steudy on women’s experiences

Sezen Demirhan

Organ transplantation stands as one of the most transformative practices in the medical field, reshaping destinies and integrating bodies into an endless project. Within this realm, the dynamics of live organ donation represent a nexus of intricate factors, including socio-cultural norms, gender dynamics, and ethical considerations. Drawing from the experiences of liver organ donors, this study employs an ethnoethnographic lens intertwined with bioethical inquiry to delve into the complexities

surrounding live organ donation. In addition, when the live organ donor data of Turkey is examined, it is striking that Turkey has consistently ranked first in the world for many years.

Using a qualitative research approach and a phenomenological design, this study engages in in-depth interviews with 18 female liver and kidney donors, aged 18 to 55 in Turkey, employing a snowball sampling technique. Unveils the profound impact of socio-cultural expectations, gender roles, and altruistic motives on the experiences of female donors.

Findings reveal how traditional notions of femininity and caregiving intersect with the act of live organ donation, shaping the experiences of female donors within patriarchal structures.

Despite facing formidable challenges and health risks, donors navigate their roles within familial and societal frameworks, renegotiating notions of responsibility and altruism.

This study underscores the need to broaden the discourse surrounding organ donation beyond its medical dimensions, emphasizing the socio-cultural and gendered aspects inherent in the process. By shedding light on the lived experiences of liver donors, this research contributes to a nuanced understanding of bioethical dilemmas and calls for a comprehensive approach to organ donation policies and practices. Otherwise, it would not be an exaggeration to claim that in the future, societies in countries like Turkey will consist of women with only one kidney.

Gene-ethics: Parallell session V

Ethical aspects of altering the processes of natural ageing

Magnus Falk

Advances in genetics and gene modification open for possibilities not only to cure and replace diseased organs or body functions, but also to modify processes associated with natural ageing. This raises some major ethical issues, not least considering an already progressing over-crowding, climate crisis and escalating socioeconomic inequities. On a globe with limited resources, who earns the right to a significantly extended life length, on the behalf of someone else? And if there existed a treatment to prevent dying from high age, who would be the medical physician to deny anyone such a treatment?

The study’s aim is to explore people’s conceptions on altering natural ageing, from an ethical perspective.

A survey was used, exploring views on different spans of life length prolongation, on the one hand as an effect of medication, and on the other hand of genetic manipulation, also asking to whom life prolongation should be enabled.

There was a more positive attitude towards life prolongation achieved by medication than by gene manipulation, but the greater life prolongation, the more problematic it was considered when achieved by the latter. Regarding whom would earn the right to interventions to prevent ageing, a majority thought that it should be made equally available to everyone wanting it, if it was a medication, whereas fewer thought so if achieved by gene manipulation.

Age prolongation is likely to become an increasingly crucial issue from an ethical perspective, in need to be discussed in advance before made possible to substantially extend longevity in humans.

How does the severity of a genetic condition affect the utility of knowing about it?

Lisa Dive, Anne-Marie Laberge, Lucinda Freeman, Eline M Bunnik

When selecting genetic conditions to include in a population-wide offer of reproductive genetic carrier screening (RGCS), severity of the condition is a central consideration – along with the strength of the genotype-phenotype association, penetrance and technical factors. Severity of the condition is important for various reasons that contribute to the justification for RGCS.

While there is agreement about what constitutes a very severe condition or a very mild condition, there is substantial complexity involved in drawing the “cut-off” line for inclusion. The concept of severity is internally complex with multiple dimensions. People's perspectives on severity can be affected by their personal and professional experiences and social norms.

When individuals and families make reproductive decisions based on genetic information, their personal perspectives on severity of a genetic condition can be integrated into the decision-making process. However for policy or program-level decisions about whether to include a condition in an offer of screening, it is more difficult to be responsive to diverse perspectives on severity.

We suggest that the concept of utility – incorporating clinical and personal utility – is a more appropriate inclusion criterion than severity. Utility places emphasis on the value of the information for purposes of reproductive decision-making, rather than requiring an appraisal of the quality of life of people who live with a genetic condition. The concept does not discard severity, as severity contributes significantly to utility, but it circumvents some of its complexity and links more directly to the purpose of RGCS and the context in which it is offered.

Research ethics – Europe: Parallell session V

Is it wrong to recycle conference contributions?

Gert Helgesson, Sara Belfrage, Jonas Åkerman

Is it acceptable to submit the same contribution to several conferences? We argue that the answer to this question depends on a number of factors that vary across research fields and conference traditions, including the expectations on conference contributions and the significance ascribed to them as publications. We evaluate the arguments for different answers including the argument that submitting the same contribution more than once would amount to self-plagiarism. Based on our conclusions, we offer practical advice for researchers and conference organisers on how to increase clarity and transparency in order to avoid misunderstandings and deviations from good research practice.

Participation in Health Tech-Based Medical Research - On Compound Burdens and Engulfment

Anna Clareborn

Human participation in research is ethically controversial, particularly in the case of medical research. The question of whether or not there is a moral obligation to participate in medical research has been subject of one particularly vigorous and long-running exchange among ethical scholars like John Harris and Ian Brassington. The debate has covered several perspectives on various duties, social contracts, social contexts, and so forth. Few of these scholars have addressed the impact of burden more in depth, however. Even fewer have considered and evaluated the special circumstances of the main class of persons participating in medical research – sick people. I want to examine three main arguments I believe work together against the duty of research for sick people – the unequal distribution argument, the compound argument, and the engulfment argument. I will use ongoing research projects in health tech as an example, in order to examine how the special burdens carried by sick people can be said to interact, potentially leading to engulfment. Furthermore, using health tech as a point of departure, I will suggest that the burden of this type of technology can be overwhelming to the extent that it weakens or eliminates the moral obligation to participate in research.

First-in-human clinical trials and participant safety: What's on and off the table in existing guidance?

Kristina Hug

In first-in-human (FIH) clinical trials an experimental intervention usually provides an insight about its tolerability. When the intervention is advanced medicinal (e.g. cell or gene) therapy or other very innovative treatments (e.g. novel anticancer medicinal products, first-time transplantations) FIH trial participants are usually patients suffering from the condition which is intended to treat. Such patients are especially vulnerable since they often lack effective treatment alternatives while being seriously sick. The decision when the state of knowledge is sufficient to launch an FIH trial can become an arena of balancing the interests of numerous stakeholders. It is an ethical imperative to safeguard that by volunteering for an FIH trial patients do not jeopardize their safety beyond what can be considered as justifiable by the expected benefit. Decision-making about launching FIH trials takes place in the realm of the existing guidelines and regulations (e.g. EMA Guidelines, EU directives) or policy statements issued by different societies. The objective of this talk is twofold:

1. To outline the state of knowledge sufficient before launching FIH trials as required in selected regulations, guidelines and policy statements from different societies;
2. To identify which, if any, safety-related issues are poorly addressed (or are left "off the table") in the analysed documents.

To achieve this objective I conduct (a) a review of the recent academic debate on this subject; (b) an overview of selected regulations, guidelines and policy statements issued by different societies with the focus on the safety of prospective FIH trial participants.

Children & medical ethics: Parallell session VI

The best interest of the child: a proposal for a taxonomy of an unclear moral principle

William Bülow O'Nils, Gert Helgesson, Ulrik Kihlbom

The best interest of the child is a principle that is commonly endorsed in both clinical ethics and in social work. According to this principle, any decision that involves children should always treat the child's best interest as a primary consideration. For example, in matters related to restricting children's and legal guardians' right to socialization in compulsory care, social workers may only restrict the parties right to socialization if doing so is in the best interest of the child. But even if it is the guiding principle, it is not entirely clear what it means to respect the principle of the best interest of the child or how this principle should be understood and applied in particular cases. To the contrary, it has been noted that the principle is rather difficult to apply and open to a range of different interpretations. In the context of clinical ethics, a few bioethicists have even suggested that the principle is superfluous and should be replaced by the non-maleficence principle. In this presentation, our aim is to understand the principle of the best interest as a moral principle (as opposed to a legal principle). Based on a literature review of the ethical literature on this topic, we present a taxonomy of a range of possible interpretations of the principle. We distinguish between formal aspects, identify a few procedural and substantial aspects concerning its possible content, and raises questions concerning its scope of application. Based on this discussion, we suggest that the principle may be understood either as an absolute principle or a pro tanto principle, as a regulative principle or a deontic principle, and as a principle given a monist or a pluralist interpretation concerning what is ultimately good for children. We then apply these points to the case of social workers decision-making when deciding to restrict biological parents' and children's right to socialization in compulsory care.

Enhancing Parental Trust in Pediatric Palliative Care

Marta Szabat

The study proposes a fresh perspective on parental involvement in pediatric palliative care, emphasizing an active form of caregiving. It builds upon prior research on parental relational agency, as detailed in the paper "Parental Agency in Pediatric Palliative Care" (published in Nursing Inquiry, 2023, doi: 10.1111/nin.12594). In this latest investigation, the focus remains on exploring the potential for a positive conceptualization of parental agency within its relational context.

The paper commences with a case study, drawing from a clinical scenario documented in the case report "Communicating with parents of children with trisomy 13 or 18 who seek cardiac interventions" (Weaver et al., 2021, doi: 10.1017/S1047951120004023). This case study recounts the challenges faced by a family whose daughter was denied cardiac surgery due to having trisomy 18, leading them to seek care elsewhere. Perspectives from parents, physicians, and interdisciplinary teams are examined, followed by an analysis of various facets of parental agency based on empirical studies.

Parental agency is depicted as dynamic and future-oriented rather than individualistic. The study focuses on repairing broken trust, particularly the trust that was compromised with the referring hospital. Drawing upon the methodology proposed by Gómez-Vírseda, Maeseneer, and Gastmans in "Relational autonomy in end-of-life care ethics" (2020, doi: 10.1186/s12910-020-00495-1), the analysis identifies ethical imperatives guiding the evolution of the care model for children with trisomy 13 and 18.

Autonomy & authenticity: Parallell session VI

Identity-Based Interpretation of 'Will and Preferences' Under the Convention on the Rights of Persons with Disabilities

Hoda Hosseiny

The presentation addresses the importance and implications of understanding the nature of personal autonomy for the right to legal capacity and support in exercising legal capacity under Article 12 of the CRPD. Article 12 challenges the long-established connection between legal capacity and mental capacity, and the concept of autonomy is no longer perceived as being linked to the capacity to reason and rationalize. This approach takes a step away from previous approaches of attributing legal capacity to cognitive capabilities. Instead, it links legal capacity to having a 'will and preference' rather than being capable of cognitive decision-making. There is, however, a fundamental challenge in the premise behind many interpretations of Article 12 that all of us have the ability to express our genuine will and preferences at any time. In other words, expressed will and preference are largely considered synonymous with genuine will and preference. Focusing specifically on the context of decisions related to the refusal of life-saving treatment, the presentation argues that, in order to determine whether a patient's decision reflects their genuine will, it is necessary to assess whether their decision stems from their true self and identity, as understood in narrative terms. The implications of such an approach will be analyzed in relation to the support requirement in the exercise of legal capacity. The significance of the arguments lies in ensuring that both patients with and without disabilities can make treatment decisions that, as much as possible, genuinely reflect who they are, thereby ensuring that autonomy is considered an inclusive achievement for all humans.

Framing of patient information to promote health care objectives – an obstacle to shared decision-making and authentic patient choice

Jenny Lindberg

Shared decision-making is the general norm in modern health care, but the existing epistemic asymmetry of the doctor-patient relationship still implies a risk of paternalism. Shared decision-making is not truly shared unless the patient makes an authentic decision based on personal preferences and value hierarchies. But is this always the case?

We conducted a qualitative study based on interviews with 14 nephrologists in Sweden. One of the findings was this: Several of the participants expressed that they support decision making and guide patient choices according to what they believe will be most beneficial for the patient. They sometimes emphasize the benefits and underplay the potential negative side effects of the treatment option they consider best, while partly demonizing other alternatives. This finding raised the need to analyze how framing in this sense relates to shared decision-making and authentic patient choice, but also to the epistemic and moral status of the patient.

Framing could encourage decision-making to promote certain values (such as health, survival, long-term well-being) while neglecting other values that the patient may personally choose to prioritize. This is clearly a form of paternalism. Framing carries the risk that the patient's choice will not be authentic in the sense that it is consistent with the patient's personal hierarchy of values. Framing can be partially misleading, that is, deceptive. It also promotes further epistemic asymmetry in the doctor-patient relationship and constitutes an attitude of diminishing the moral status of the patient.