



EACME Newsletter

EUROPEAN ASSOCIATION OF CENTRES OF MEDICAL ETHICS

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EDITORIAL

EDITORIAL

Dear EACME colleagues and friends,

Even though summer has brought us warmer temperatures and hopefully some joyful activities during our summer breaks, the COVID-19 pandemic still poses a range of ethical challenges, among them vaccine hesitancy in various countries, nationalism in vaccine distribution and ongoing national isolation resulting in reduced international travel.

Adapting to the current situation, the EACME conference in Cluj will be held in a hybrid format this year with the possibility of participating either onsite or online. In the future, this new format will surely provide opportunities for those who are not able to attend such events in person, making conferences even more inclusive.

In this edition of the EACME Newsletter, Maria Aluas provides some introductory information on this year's conference. In addition, the authors cover topics relating to the ongoing COVID-19 pandemic, such as the use of artificial intelligence for anti-covid vaccines by J. Agnolucci & L. Caenazzo and a perspective on applying pandemic ethics to the pandemic by S. Cox.

Apart from that, J. Martin presents an argument for responsibilities of health care professionals towards the climate crisis and G. Birchley and N. Bhatia present their newly established network to address the challenge of paediatric medical tourism.

We also have another permanent section in the newsletter: Beside the section where PhD students can present their theses, the new section highlights EACME member institutes – first new members and then existing ones. In this issue, H. Soofi presents his PhD thesis on the ethical sides of antipsychotic treatment in dementia care, while R. Jox and E. Martinez introduce the Lausanne Institute of Humanities in Medicine, Switzerland – our new EACME member institute.

On behalf of the editorial board we wish you a fruitful and enriching EACME conference 2021 – this time both online and in person.

Very best wishes,
Caroline Brall

NEWS FROM THE EACME BUREAU

Dear EACME members,

We hope you could enjoy the summertime and managed to take a break from work to spend time with friends and family!

We are very happy that socialising has become easier again, and public spaces and life could somehow resume in most European countries. We hope things will further continue improving despite concerns raised by vaccine fatigue, hesitancy or refusal as well as unequal access to vaccination programmes.

Uncertainty remains part of our daily-life and also impacted this year's conference planning. We are grateful about Maria's unshakable optimism to run the conference as a hybrid event allowing participants to make last-minute decisions as to whether they will join online or on-site. The conference planning has been without a doubt one of the most challenging in the history of the EACME, and we want to thank Maria and her team for a wonderful programme. To quote Rouven, "the programme looks like we would have just a normal EACME conference", – and we are indeed very confident that despite the unusual hybrid model and the challenging circumstances, Maria will make it feel like any

other conference, just a bit more exceptional and special!

As already mentioned in our email to all member centres, we decided to hold the General Assembly Meeting virtually on the Monday after the conference, 13th September to avoid Zoom fatigue during the conference. We hope you understand our decision. Next year, hopefully, we will be back to the normal schedule again.

Even though not all Bureau members will be able to travel on-site, due to ongoing travel restrictions at some Universities (Varese and Amsterdam), we very much look forward to welcoming you either in person in Cluj or online.

With best wishes,

Ruth, on behalf of the Bureau (Kim, Bert and Federico)

PS: Keep an eye out for our next EACME Webinar which will take place on November 11th 2021 at 5pm!

Information on the EACME Conference *Smart Ethics in Transylvania* 9-11 September 2021, Cluj-Napoca, Romania

Maria Aluas

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Due to the COVID-19 pandemic the planned 2020 EACME conference was postponed, in order to figure out how to organize such event given the circumstances, but also keep participants and organizers safe from possible infections. This year we will be offering participants the flexibility to choose between attending the conference venue – which is at the Iuliu Hatieganu University of Medicine and Pharmacy, Cluj-Napoca (Romania) – or joining the event virtually through the online event platform.

We choose to organize a hybrid conference because we would like it to be as close as possible to an onsite event, offering participants the opportunity to attend the conference in person, while also following, at the same time, the latest government guidance to ensure that the conference is a safe place for guests, participants and organizers.

Participants attending the venue will be able to watch the plenary sessions live and there will also be dedicated viewing auditoria at the venue providing the opportunity to watch the virtual streams. The online platform is fully mobile compatible, giving on-site participants the

flexibility to watch all the lectures, to participate in discussion sessions and network 'on the go'.

The virtual conference platform will recreate the buzz of a live event and gives online participants the flexibility to attend the EACME Annual Conference at a time and place that suits them. On the virtual platform you will find live broadcast of all the talks; recordings of plenary sessions which are available during the three days of conference and a week after the event; as well as networking opportunities.¹

Our goal is to provide a suitable and as good as possible event for all who will join the conference in one of the two forms, using an adaptable hybrid platform, with a virtual tour of the venue and parallel sessions rooms, which can facilitate interactions between all participants during this event.

From now on, we all must learn how to behave and to handle such events and to integrate what we live and learn during Covid-19 pandemic restrictions in our personal and professional life.

¹

Artificial Intelligence, Vaccines and COVID-19 Pandemic

Jacopa Agnolucci and Luciana Caenazzo
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More than a year after the first documented case of SARS-CoV-2 infection, the worldwide count of COVID-19 cases and deaths shows no sign of stopping². An important turning point in the fight against the Coronavirus has been achieved with the development of the first vaccines. The objective of the EU Vaccine Strategy is to vaccinate almost 70% of the entire European adult population by summer 2021³. Achieving this goal also means guaranteeing the quality, safety and efficacy of vaccines; ensuring timely, equitable and cost-effective access to them; addressing transport and distribution needs, and identifying priority groups that should gain access to vaccines first. Faced with these needs, set in the context of a pandemic emergency made even more complex by the scarcity of available doses, artificial intelligence (AI) could provide important help^{4,5,6}.

As defined by John McCarty, artificial intelligence “is the science and engineering of making intelligent machines, especially intelligent

computer programs. It is related to the similar task of using computers to understand human intelligence, but AI does not have to confine itself to methods that are biologically observable”⁷. Nowadays AI are widely used in numerous fields, from health care to cybersecurity and national defence.

Regarding the specific issue of the SARS-CoV-2 pandemic, according to experts from the Institute of AI and RiSE (Research in Societal Enhancement) group of the De Montfort University (Leicester, UK), AI systems could efficiently generate priority lists using probability modelling, with relatively low data requirement. This model could help countries and organisations that have less sophisticated data systems in place too, granting that the order in which they roll out the vaccine is reflective of the actual probability of their people dying and/or being infected⁸. Many IT companies such as Microsoft, Google and IBM have developed AI and

² <https://covid19.who.int/>

³ EU Vaccine Strategy. Accessible at: https://ec.europa.eu/info/live-work-travel-eu/coronavirus-response/public-health/coronavirus-vaccines-strategy_en#:~:text=Speeding%20up%20vaccination%20in%20the%20EU,-On%2019%20January&text=By%20March%202021%2C%20at%20least,of%20the%20entire%20adult%20population

⁴ Adler, K. EU closes ranks over Covid surge and vaccine delays. BBC, News, World, Europe. March 13th, 2021. Accessible at <https://www.bbc.com/news/world-europe-56361840>

⁵ Covid: What is happening with the EU vaccine rollout? BBC, Explainers. June 21st, 2021. Accessible at <https://www.bbc.com/news/explainers-52380823>

⁶ Crisp, J. Chaos in Europe over AstraZeneca. The Telegraph, News. March 16th, 2021. Accessible at <https://www.telegraph.co.uk/news/2021/03/15/germany-becomes-latest-country-suspend-use-astrazeneca-vaccine/>

⁷ McCarthy J. What is artificial intelligence? Stanford University; 2004.

⁸ DMU. Researchers argue that Artificial Intelligence can help decide who gets a Covid-19 vaccine.

January 12th, 2021. Accessible at <https://www.dmu.ac.uk/about-dmu/news/2021/january/researchers-argue-that->

cloud-based technologies to support governments in numerous aspects of the vaccination campaign, from logistics to analytics, communication, forecasting and modelling to predict the future trend of the pandemic, with the aim of implementing the availability of vaccine doses and the fairness of their distribution while ensuring the construction of greater awareness, confidence and acceptance of vaccines in the population. These tools, such as Google Cloud's Intelligent Vaccine Impact Solution (already applied in some states of the U.S., such as North Carolina) and Microsoft's Vaccination Registration and Administration Solution, are based on machine learning systems that combine AI with fundamentals of epidemiology to create what-if analysis models and forecasts about the pandemic. Other components of these solutions consist of: information portals to provide correct information on vaccines to people while allowing them to determine their eligibility for vaccination and the subsequent possibility of booking and managing the appointment; real time tracking of vaccine batches with monitoring of their conditions, maintenance temperature in the first place, a fundamental condition for the conservation of vaccines currently available, but also their quantity and their position; systems for displaying specific risk criteria by population so as to optimize the distribution priority for distributors; reports on the efficacy of vaccines; tools with the important purpose of understanding the feelings of local communities

[artificial-intelligence-can-help-decide-who-gets-a-covid-19-vaccine-first.aspx](https://blogs.microsoft.com/blog/2020/12/11/successful-covid-19-vaccine-delivery-requires-strong-tech-partnerships/)

⁹ Daniels, M. Getting vaccines into local communities safely and effectively. Google Cloud Blog, Healthcare & Life Sciences. February 1st, 2021. Accessible at <https://cloud.google.com/blog/topics/public-sector/getting-vaccines-local-communities-safely-and-effectively>

¹⁰ Rhew, D. Successful COVID-19 vaccine delivery requires strong tech partnerships. Official Microsoft Blog, December 11th, 2020. Accessible at

about the risks and benefits of the vaccine and responding to them in a fast and targeted manner^{9,10}. All this with the ability to control and manage information in real time, ensuring both transparencies, in a complex context of data sharing between public bodies and private companies, and privacy of individual citizens who must retain control over their own information, without neglecting the need to protect such data from cyber-attacks¹¹.

Recently, AI are also being used to help with another issue related to the pandemic: COVID-19 vaccine hesitancy. Counted by the WHO (World Health Organization) among the ten threats to global health in 2019, vaccine hesitancy is defined as “the reluctance or refusal to vaccinate despite the availability of vaccines – threatens to reverse progress made in tackling vaccine-preventable diseases”¹². IBM Research and Johns Hopkins University unveiled a new artificial intelligence-powered chatbot named Vira - short for Vaccine Information Resource Assistant - to combat COVID-19 vaccine hesitancy. The chatbot, which has been trained using a database of more than 150 distinct concerns about COVID-19 vaccines, recognizes the many thousands of ways different people can express these key points and it learns and improves based on user feedback to reassure them of the

<https://blogs.microsoft.com/blog/2020/12/11/successful-covid-19-vaccine-delivery-requires-strong-tech-partnerships/>

¹¹ Kelley, J. A Groundbreaking Vaccine Will Need a Groundbreaking Supply Chain. IBM Newsroom. November 12th, 2020. Accessible at <https://newsroom.ibm.com/A-Groundbreaking-Vaccine-Will-Need-a-Groundbreaking-Supply-Chain>

¹² WHO. Ten Threats to global health in 2019. Accessible at <https://www.who.int/news-room/spotlight/ten-threats-to-global-health-in-2019>

safety of the vaccines while still providing evidence-based information^{13,14}.

The introduction of AI in this context raises also new challenges including identifying who could be held accountable if an error occurs due to an “AI mistake”. In December 2020, an algorithm was used at the Stanford Medical Centre to assign the first vaccine doses obtained, but contrary to expectations, it turned out to be unfair giving greater priority to age rather than to the real probability of contracting the infection based on work activity, effectively excluding young staff who worked on the front line. To protect from such eventualities, most data scientists and AI researchers claim that the only solution is more transparency from companies that design algorithms, which is quite rare due to the complexity of the algorithms themselves or due to trade secret¹⁵. In parallel, it is important to develop AI-systems in accordance with ethical principles, such as beneficence, non-maleficence, justice and trust¹⁶. The pandemic emergency may not allow this complex issue to be defined correctly and in time, but soon the issue of AI regulation will have to be addressed, as the CAHAI has proposed to do by 2028 (ad hoc Committee on Artificial Intelligence), under the authority of the European Committee of Ministers, “in order to find a fair balance between the benefits of technological progress and the protection of our fundamental values”¹⁷.

WHO (World Health Organization) itself took a move and worked with a leading group of twenty experts to identify core principles to promote the ethical use of AI for health, creating and releasing on June 28th, 2021 the first global report of its kind, “Ethics and governance of artificial intelligence for health”, as a result of a two-year development process led by two Departments in the Science Division - Digital Health and Innovation and Research For Health. In this report the experts point out six core principles which are the first consensus principles in this field: (1) Protect autonomy; (2) Promote human well-being, human safety, and the public interest; (3) Ensure transparency, explainability, and intelligibility; (4) Foster responsibility and accountability; (5) Ensure inclusiveness and equity; (6) Promote AI that is responsive and sustainable. Well aware of the enormous potential of AI and advantages deriving from their use, both for wealthy and resource-poor countries, the WHO experts in this report warn “against overestimating these benefits, especially when this occurs at the expense of core investments and strategies required to achieve universal health coverage”, recalling once again that “opportunities are linked to challenges and risks, including unethical collection and use of health data; biases encoded in algorithms, and risks of AI to patient safety, cybersecurity, and the environment”¹⁸.

¹³ Drees, J. Johns Hopkins, IBM launch AI chatbot to combat COVID-19 vaccine hesitancy. Becker’s Hospital Reviews, Artificial Intelligence. July 1st, 2021. Accessible at

<https://www.beckershospitalreview.com/artificial-intelligence/johns-hopkins-ibm-launch-ai-chatbot-to-combat-covid-19-vaccine-hesitancy.html>

¹⁴ <https://www.vaxchat.org/faq>

¹⁵ Harwell, D. Algorithms are deciding who gets the first vaccines. Should we trust them? The Washington Post, Technology. December 23rd, 2020. Accessible at <https://www.washingtonpost.com/technology/2020/12/23/covid-vaccine-algorithm-failure/>

¹⁶ Kadircan H. Keskinbora. Medical ethics considerations on artificial intelligence. Journal of Clinical Neuroscience. 2019; 64:277-282.

¹⁷ Kleijssen, J. How to regulate the development of artificial intelligence? Council of Europe, Artificial Intelligence. Accessible at <https://www.coe.int/en/web/artificial-intelligence/statement-jan-kleijssen>

¹⁸ Ethics and governance of artificial intelligence for health: WHO guidance. Geneva: World Health Organization; 2021.

Pandemonium Ethics a Practical Approach to Discussions about the Pandemic

Shereen Cox
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Medical ethics is still evolving. Much of the work done by ethicists are now bearing fruit. Many universities incorporated ethics into the curricula of healthcare professionals and researchers received formal training of academics in research ethics and research integrity. It is now 2021, and the world is managing a global pandemic. Were we preparing for a pandemic and the effects it could have on our lives? The COVID-19 pandemic is no doubt one that will be talked about for decades to come. The events of the past eighteen months have challenged everything as we know it. Theoretical ethics is put to the test – and many have to revisit their own moral positions when faced with the challenges, both personal and professional, of the pandemic. It is easy to look at the medical atrocities of the past through the eyes of judgment and condemnation. However, now we are in the midst of our own crisis. Some of our colleagues or loved ones are on the front line. Millions of lives were lost. We struggled with the worldview of those closest to us. They send us conspiracy theories and questions such as: Is COVID-19 fabricated? Are the vaccines a form of genetic manipulation to exert control? Are we part of the largest clinical trial in history? Are human challenge studies appropriate? Were the vaccines rushed? Are they safe? Are vaccine nationalism, vaccination passports, and vaccine lotteries ethically acceptable? Why are governments not approving repurposed drugs that are cheaper? Everything is being questioned. Science and scientific evidence is being challenged like never before. People are

dying, economies are struggling, and hope is desirable but appears far way off. The only word that seems appropriate to describe this situation is pandemonium.

Cambridge online dictionary defines pandemonium as *a situation in which there is a lot of noise and confusion because people are excited, angry, or frightened*. This seems to be the order of the day – The COVID-19 has created confusion and evoked various emotions. In an interview on MSNBC on June 9, 2021, Dr. Fauci, National Institute of Allergy and Infectious Diseases director (USA), said that everything he says is “taken out of context” and “science and truth are being challenged.” People are talking over each other. Listening is not to understand but to offer a rebuttal. Educated, semi-literate, uneducated all have strong opinions and emotions about COVID-19 and vaccination. Later that same day, a colleague of mine in a WhatsApp group sought my opinion as an Ethicist about the launch of a vaccine lottery promotion by one of the leading lottery companies in the Caribbean. The learned opinion was shared, but quickly others countered with their strong opinions on vaccination and incentives. These are all highly educated persons yet on opposing sides of the vaccine agenda. Pandemonium.

In some countries, governments and employers are offering money, land, food in exchange for persons to be vaccinated while some countries are waiting on the wealthier countries to allow them to get what they can spare. Herd immunity

is the goal, and the sooner the better for the economy, better for the world. It seems we need a pandemonium ethics - ethics for times when things are genuinely confusing, to help us navigate to the right path. Now before my esteemed ethics colleagues challenge me, please note that I am not suggesting a new ethical theory. I am suggesting a way to approach discussions and find solutions when persons are divided, distressed, and discouraged. Think of a lighthouse guiding the shipwrecked sailor home. People are disinclined to hear ethical theories and the kind of language that is taught in schools. What may be necessary are ethicists assuming the roles of observers and discourse facilitators and less as academicians. Perhaps a return to the way of the ancient philosophical dialogues of Socrates and Plato. On the one hand, asking the important questions that somehow guide the students to the answers, or on the other, assuming the role of advisors. It is generally understood that ethicists ought to offer advice; it is why we were trained. However, I am proposing, concerning the most affected by this COVID situation, accommodating the views of the people around us – our families, friends, neighbors, religious communities, and professional organizations. Many of these persons do not want a know-it-all; they seek mediators because they are genuinely fearful of the future. It is very easy to label an anti-vaxer as absolutely wrong and ridiculous, but the reality is that the anti-vaxer is a person who has made an autonomous decision, likewise, for those who

are vaccine-hesitant. We often, as ethicists, emphasize informed consent, but the comparative discussions about informed refusal and its implications are not given equal consideration. An anti-vaxer in the spirited WhatsApp discussion mentioned earlier, asked about the Nuremberg Code and its emphasis on informed consent – he/she suggested that informed consent was his/her right to exercise or reject. For that conversation, as the Ethicist in the group, I assumed the role of mediator, thereby facilitating opposing arguments, creating the balance needed to manage emotions (equanimity), and allow individuals to exchange perspectives.

Equanimity, the state of calmness and composure in difficult situations, was the central focus of ancient Stoic philosophy. This viewpoint on pandemonium ethics may just be borrowed from the ancient Stoics. I visualize this form of ethics as being calm and undisturbed by the various perspectives floating around and the Ethicist assuming the role of the student, the observer, the mediator, or the facilitator. Pandemonium ethics is perhaps what we need for this pandemic. A stoic attitude to hear all arguments, to practice what we have been teaching. Perhaps this pandemonium will help us learn approaches that could allow us to grow, teach, and become better ethicists.

Climate and (bio)ethics

How to act and take into account the impact of climate change, both in personal health care and public health?

Jean Martin

Former member of the Swiss National Commission on Bioethics

There is no possible doubt that the challenges thrown to us by climate warming ask for major changes in the way our societies function; in the fields of energy, industry, economy, finance, agriculture, mobility etc. Regarding the covid pandemic, the Western world might be currently (summer 2021) seeing the end of the tunnel, though there is no certainty there (fourth, fifth wave?). And there are indications that much of society craves to go back to functioning just as before. To return to the way things were - the “normal” ways... However, these former ways should be considered abnormal when considering its damages to climate and biodiversity (proclaimed by a French saying, “Pas de retour à l’Anormal” - let’s refuse to go back to the abnormal).

While in several countries there has been a significant greening of societal and political life in recent years, it is not clear that forceful enough measures (legislative, operational) will be taken - or whether we’ll see strong resistance to measures impacting upon people’s way of living - representing costs, hindrances, limits... In Switzerland, a major “Carbon dioxide law” was rejected by popular vote (referendum) in June 2021. One issue deserving attention is concerns with dramatic planetary events versus concerns about one’s monthly pay check (which might be potentially burdened by additional taxes). This

trade-off certainly will emerge repeatedly in coming years.

What are related ethical challenges for members, particularly teachers, of the health professions - including ethicists? In our part of Switzerland, we have a dynamic “Doctors4XR” section - XR referring to the Extinction Rebellion movement, launched in 2018 in the UK. On May 29, 2021, 200 health professionals were received at WHO Headquarters by Dr Tedros, Director General, who indeed showed interest and commitment about climate issues. These “white coats” were led by several senior doctors and university medical teachers, in particular Prof. Valérie D’Acremont, from Lausanne, infectious diseases and tropical medicine specialist. They handed Dr Tedros a letter signed by over 1000 professionals. In her speech, Prof. D’Acremont asked the WHO Director General to insist that Member States take more vigorous action on climate change. “Health authorities must make the consequences of climate change and biodiversity loss the number one public health issue and support the declaration of a state of emergency for climate and biodiversity”, she said.

The general picture is well described - and regularly updated - in the “Lancet Countdown on Climate and Health”. While the emergency is not

as sudden as the COVID pandemic, climate linked damages to health will be substantially growing - and it is absolutely clear that, in terms of future morbidity and mortality, the losses due to global warming will be of a much larger magnitude.

It thus appears urgent that ethicists in the health sector dedicate deliberation about the actions the situation demands. Over the last years and decades, there has been extensive attention given to ethical issues in person-to-person care (assistance to reproduction, organ transplant, competency, palliative care and end of life among others). The current pandemic has demanded consideration of public health ethics issues like access to intensive care, possibly triage, and immunization (including distinctions to be made in these regards among different groups).

Climate change brings with it a large amount of ethical conundrums, especially of a public health nature. This is to a large extent with respect to society and politics (as life in the polis, as “res publica”). Reference can be made to the Latin maxim “Salus publica suprema lex”, in evidence in a number of parliament’s halls - which responds to “Salus aegroti (the patient’s health) ultima lex” of clinical practice. This is in line with Rudolf Virchow’s famous quote “Medicine is a social science and politics is nothing else but medicine on a large scale”

The current situation calls for an active involvement of health professionals. First, the health system should be reorganised in such a way that it reduces its greenhouse gas emissions - there is much to reduce, reuse, replace, repair,

recycle. Next, and most importantly, action should be taken on the public level. Generally, health professionals enjoy respect, consideration, even prestige (though it is true that the situation has evolved in recent decades and people feel free to ask questions or confront the doctor). Research has shown that the population still trusts their health care professionals, giving these professionals a special mandate to take part in developing and implementing the changes - small and large - that the crisis requires.

Here, what about “neutrality”, the principle that health professionals keep some distance, are empathic while keeping adequate reserve, may be close but not too close? This is a significant part of the professional’s stance. There might be a tendency to keep the same “distance” when dealing with societal issues, yet the present climate and biodiversity challenges are such that we cannot just observe from the side-line. Confronting the issues, vis-à-vis society and, as feasible, vis-à-vis the patient, is now needed. Because many patients and the communities around them will be made more and more fragile by climate warming. And because health professionals are entitled and, more than that, should firmly take positions in support of people who are not able to adequately defend themselves, fight for their rights and interests. That’ll be the case for many as the situation worsens.

Though not limited to health aspects, questions surrounding climate transformation should find a place in the curricula and practical training

Paediatric medical tourism – a network to address the challenge

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Paediatric medical tourism – the movement of children over international borders for healthcare treatments – is a growing area of practice linked to globalisation of healthcare markets. Unlike the movements of adult patients who seek treatments in other countries, it remains largely unresearched.

Parents seek providers in other jurisdictions for a wide variety of reasons. These range from migrants returning to their country of origin because they are more familiar with the healthcare system; parents seeking treatments that are not available in their home country (ranging from treatments with a good evidence base to treatments that are entirely undocumented and of dubious safety), and; so-called “circumvention tourism” where parents seek a treatment that is illegal in their home country.

The internet and social networking have made accessing a global market in treatment much easier, because many providers have a web presence, and almost any treatment can be found rapidly using the normal search engines. While international travel is relatively cheap, the advent of widespread crowdfunding provides a source of fundraising so that even costly treatment is accessible.

Despite the fact that all but a small amount of

paediatric medical tourism is undertaken for reasons for which we can be sympathetic – to improve the health of a child – it raises a number of concerns:

- i) Where health tourism is from a wealthy country to a country with a low or middle income, the use of limited health resources on incoming health tourists may create scarcity for local populations and exacerbate global inequalities.
- ii) The international healthcare market is crowded, and it is difficult to make a properly informed choice. There is little to distinguish charlatans from legitimate providers. Few international accreditation schemes exist, and there are many clinics worldwide offering miraculous, but entirely unproven – treatments like stem cell transplants or gene therapy. Such treatments trade entirely on the hopes of patients, including families of children with chronic or life-limiting conditions, that are unlikely to be fulfilled.
- iii) The lack of accreditation also means that it is difficult to distinguish good providers from bad, even where treatments are legitimate. There is often little if any long-term relationship between providers and patients, and thus little

follow up if things go wrong in the medium or long term.

- iv) There are few reciprocal legal agreements and when things go wrong. Different jurisdictions have dramatically different legal approaches to medical paternalism, medical liability, and redress for harms. It may be impossible to claim compensation or enforce its payment across international borders (even with in the European Economic Area).
- v) Different countries have different attitudes to the scope of parental rights over their children's healthcare, and how these should be balanced with risks and limitations of treatment. This risks a 'race to the bottom' for children's rights to dignity and freedom from undue suffering in situations where burdensome treatments or miraculous cures are offered.
- vi) The use of crowdfunding to raise funds invites ethical concerns in its own right, because of the necessity to disclose the child's private health information in order to raise funds. Crowdfunding is linked to a lack of equitable access to healthcare, with the most publicly sympathetic cases likely to raise the greatest funds.
- vii) Healthcare professionals in the originating country may either feel or be in a vulnerable legal and ethical position when they provide aftercare for negligent or illegal treatments.

The current situation is thus clearly unsatisfactory, but there are at least three major challenges in addressing paediatric medical tourism.

- i) There is little hard data about the problem. Flows of patients into and out of different countries are largely

unknown, economic impacts remain to be investigated, as do the reasons different families choose to travel, where they look for information and how they choose providers.

- ii) The problems raised are complex and hard to pin down. The phenomena of paediatric medical tourism is multifaceted and demands a range of responses. Travel to access illegal treatments may invite multinational agreement, but only if a legal or ethical consensus exists about the treatment. As the medical ethics community well knows, there is plenty of ethical as well as legal disagreement about, for example, termination of pregnancy, euthanasia or puberty blocking drugs. Travel to access legitimate treatments requires international systems of validation so that legitimate treatments are identifiable, and the strengthening of international accords on the rights of health consumers. Yet such an approach may compete with global economic justice if it benefits only the consumers of wealthy countries, given that global travel is much more difficult for people in low- and middle-income countries, even if they have funds available.
- iii) Finally, while there is baseline agreement that the rights of children should be protected, given the near-unanimous global endorsement of the UN Convention on the Rights of the Child 1989, there is significant disagreement about how the provisions of the UN Convention should play out in individual cases where parents seek to prolong the lifespan of a dying child or expose a chronically ill child to risky or burdensome treatment.

As a first tentative step toward addressing these problems, we are establishing an international network, with representation from a wide range of disciplines and institutions. A network will provide the connections and the collaboration opportunities to allow problems to be identified and investigated on an international front. If you would like more information, or better would be

willing to join us, please contact us or use the following link to share your details!

<https://www.bristol.ac.uk/population-health-sciences/centres/ethics/research/the-children%E2%80%99s-medical-tourism-research-network/>

Ethical permissibility of AP treatment for residents with behavioural and psychological symptoms of dementia (BPSD) in residential aged care facilities (RACFs)

Hojjat Soofi, Macquarie University, Sydney, Australia

Along with cognitive deficits such as memory loss, almost all people with dementia develop at least one type of non-cognitive symptoms such as agitation, aggression, anxiety, sleep disturbances, depression, delusion, and hallucination (1). Collectively these are known as BPSD (behavioural and psychological symptoms of dementia).

The presence of BPSD is associated with poorer quality of life in people with dementia (2) and may result in early institutionalization of individuals with dementia (3). Management of BPSD is considered the most challenging aspect of dementia care by caregivers (4). There is a strong positive correlation between BPSD and caregiver burden and distress (5).

Currently, antipsychotic (AP) medications are the most commonly used pharmacological intervention to manage BPSD in residential aged care facilities (RACFs) (6, 7). The existing body of evidence, however, indicates that AP medications may have at best modest efficacy for managing BPSD (8, 9). Further, there is considerable evidence that AP treatment in people with dementia may be associated with a greater probability of adverse effects such as extrapyramidal symptoms, serious cerebrovascular events, upper respiratory tract infection, over-sedation, drowsiness, and falls (10-12). Previous research has also shown that the use of APs varies in RACFs and such variation cannot be explained by differences in residents' clinical characteristics (13).

These observations raise the questions that whether, and under what circumstances, AP treatment for residents with BPSD in RACFs might be ethically permissible. In the existing academic debate, a range of rationales both in favour and against the practice have been provided. Some of the ethical rationales against the practice are the following. First, it is argued that the use of AP medication should not be pursued as a means to chemically restrain people with BPSD (14). Second, some scholars hold the view that that the use of APs can potentially compromise the personhood of residents with dementia in RACFs (15).

There are, however, some proposed ethical rationales for the use of APs in RACFs. First, it is suggested that undertreatment or nontreatment of BPSD might compromise the dignity or personhood of people with dementia (14), and that there are harms arising from leaving BPSD untreated (16). Second, some maintain that AP treatment in small doses is ethically permissible in situations in which a resident with BPSD acts in such a way that puts in danger her life or the life of her fellow residents (for example, in cases of resident-to-resident aggression) in RACFs (17).

The above ethical rationales, nonetheless, raise further conceptual and practical questions. One set of questions are what forms of AP treatment count as chemical restraint, what is the main ethically problematic aspects of chemical restraint in the context of care in RACFs, and whether chemical restraint of residents with dementia in RACFs is always ethically unjustifiable. According to common definitions of chemical restraint (18), some uses of APs to avert threats of harm to other residents in RACFs or to manage self-harming behaviour do seem to count as chemical restraint. But it is not clear that just because such uses of APs count as chemical restraint, they can be judged as ethically impermissible practices.

Another set of question is what notions of dignity and personhood lie behind the proposed ethical rationales for and against the use of APs for people with BPSD in RACFs. Unfortunately, so far in the existing debate, scholars have not clarified in detail their working notions of dignity and personhood and the role that such appeals to personhood and dignity should play in assessing the ethical permissibility of AP treatment for residents with BPSD in RACFs.

These unsettled issues indicate that the current debate needs further overt and detailed ethical analyses. Further scholarly work might help build a stronger case for the ethical (im)permissibility of using APs to manage residents with BPSD in RACFs.

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New EACME Member: The Lausanne Institute of Humanities in Medicine (Switzerland)

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Slowly but steadily, the European Association of Centres of Medical Ethics (EACME) is growing. Currently counting 65 members in 21 countries, it has recently welcomed the Lausanne Institute of Humanities in Medicine (Institut des humanités en médecine, IHM) as a full member. We take this opportunity to briefly present the IHM and invite the readers of the EACME newsletter to get in contact with us.

The IHM, directed by Vincent Barras, has been created three years ago on the basis of an institute of history of medicine and public health that had existed since 1990. Thanks to a unanimous political will of the local government, the university, the medical faculty and the university hospital, the joint strategy is being pursued to develop a strong field of humanities in medicine in Lausanne. As a consequence, the IHM has been significantly enlarged and diversified over the past three years: it currently has 4 academic axes: (1) history of medicine and public health, (2) sociology and anthropology of medicine and health, (3) ethics and philosophy of medicine and health care, and (4) applied

humanities including hospital communication sciences and spirituality in medicine. The last discipline that is about to be added to this

multidisciplinary array is medical law and law of the life sciences.

With 4 professors, 16 researchers, 30 PhD students and a well-staffed administration, the IHM is a vibrant institute that tries to realize true interdisciplinary and transdisciplinary activities, both in research and teaching. Besides an academic lecture series with distinguished international speakers and various conferences, it also organizes a monthly research seminar focusing on methodology and ongoing projects, as well as an annual research symposium. With the help of the IHM, the University of Lausanne is launching in September 2021 a new PhD programme specifically focused on humanities in medicine (“PhD in humanities and social sciences of medicine”).

In the field of medical ethics and philosophy of medicine, headed by Ralf Jox, a broad range of

topics is covered, with a focus on clinical ethics, care ethics, end-of life ethics, technology and neuroethics, as well as foundational concepts of medicine.

The IHM also hosts the Clinical Ethics Unit, which offers health care ethics consultation activities within the Lausanne University Hospital, collaborating closely with its Geneva counterpart (headed by Samia Hurst) and participating in the European Clinical Ethics Network (ECEN). Current research projects cover the issues of advance care planning, decision-making in acute stroke care, palliative sedation, assisted suicide, moral distress in research nurses, Covid-19 pandemic policies, care robots, disability and the phenomenology of the human body.

A distinct feature of the IHM is that it forms part of the Lausanne University Hospital (CHUV), recently distinguished by the US magazine Newsweek as one of the top-ten hospitals in the world, as only one of three European hospitals. This embeddedness into the clinical environment allows close links to clinicians and clinical researchers. Among the 91 researchers

that are formally associated to the IHM there are both international partners and local clinicians. At the same time, the IHM has close links to the regional and national public health bodies, which regularly entrust IHM researchers with specific mandates and counselling activities.

Finally, the IHM is also known for its large collection of historical objects and its library (<https://bihm.lescollections.ch>): among the 50'000 books are not only historical and medical ones, but also a large collection of medical ethics and medical philosophy, funded by the local Chassot and Gueux Foundation (almost 3000 books).

The IHM is grateful and happy to join all the other EACME members and looks forward to collaborating with them. Situated in the heart of a beautiful university city at the shores of the Lake of Geneva, the IHM always welcomes guests, visiting scholars and collaboration partners. If you have any questions regarding the IHM or its medical ethics activities, do not hesitate to contact Ralf Jox or Elena Martinez.

DEADLINE NEXT NEWSLETTER

The deadline for the third edition of 2021 is:

December 1, 2021

Publishing in this newsletter is an opportunity to promote your event, to inform your EACME-colleagues about the results of your work, descriptions of projects, book reviews etc.

Any ideas for contributions for the upcoming edition?

Please get in touch and do not hesitate to contact our editor Caroline Brall:

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