

EACME Newsletter

European Association of Centres of Medical Ethics

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EDITORIAL

It is with great pleasure I present to you the August edition of the EACME newsletter. Within its pages you will find the usual collection of book reviews, reports and articles, but in this special issue the editor and bureau have chosen to have a special focus on the COVID-19 pandemic. This had arrived with force in most of Europe at the time of the last newsletter, in April. It is now August and, a level of control has been established over the spread of the virus in Western Europe, in many cases by enforcing strict lockdowns on the movement of the population. Control has been marked by, in most countries, residual levels of transmission with intermittent spikes in infection. In some countries this has been counted in handfuls of new cases, while in others, hundreds of new cases are recorded each day. The situation remains in balance, and it appears the virus will be with us for some time.

We will all have developed insights and understandings from reflecting on our own experiences of lockdown so far in the pandemic. For some, who have lost love ones, the impact will be profound. For others lockdown will have given too much or too little social isolation, as the normal benefits and separations of work and home life have been broken down: to this extent, many of us will have experienced different lockdowns, yet all will be reminded that we are at heart creatures who are vulnerable to changes in our social environment as much as to our own states of mind. This, then, is a change in perspective wrought on (at least some) academic medical ethics by the pandemic, where the prior focus on micro-interactions between individuals draws back to reveal the panorama of interconnectedness and mutual vulnerability. Historians of philosophy tell us that past societal traumas have in the past ushered in profound changes in the

directions of theory: the US philosopher and jurist Jeremy Waldron¹ has argued that the wake of the 18th and 19th century revolutions of Europe caused the abandonment of the enlightenment focus upon individual rights, ushering in the focus on the life of society as a whole. This led to the work of Marx, Durkheim and Weber. Waldron argues that it was only tectonic impact of the events of the Second World War that caused policy makers and theoreticians to return their focus to the individual. While COVID-19 is clearly different from the French Revolution, the huge challenges of COVID-19 are only just at a beginning. A pandemic still ravages the world, while a global recession of gigantic proportions threatens to deepen the wounds already left by the savage impact of the global economic crisis. The prevailing consensus of economic and social liberalism was already teetering. Change may indeed be needed, but change can sweep aside things of value as easily as things without. We must all use our voices to ensure that the advances of the past – toleration, liberty, rationality – are defended and preserved amid whatever change follows.

As we head into this great unknown, the reports in this issue give us some insight into what the medical ethics community have been focused on in the past, and coming, months. We hear reports from centres in Switzerland, Germany, Italy and England about such pandemic related issues as the problems of lockdown on vulnerable populations such as prisoners, persons with disabilities, and migrants, tensions in national policy, impacts upon privacy and personal testimonies from the healthcare frontline. I end this editorial on a personal note: it is time for me to say goodbye as editor, a role which I have performed since taking over from Rouven Porz in Autumn 2016. The next newsletter will see Dr Caroline Brall take over as editor of the EACME newsletter. Caroline is based at the Health Ethics and Policy Lab, Department of Health Sciences and Technology at ETH Zurich – I am sure you will make sure her first issue as editor of the newsletter is marked by a flurry of articles and reports of the best quality!

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¹ Jeremy Waldron (1987). Nonsense upon Stilts. London, Methuen.

NEWS FROM THE EACME BUREAU

Announcing our virtual conference “Ethics in pandemic times” September 11, 2020, 13.00-15:00

Dear EACME Members,

What a strange year. And how quickly we've all managed to 'adapt' to the new Corona 'lifestyle'. We travel less, teleconferencing is booming, and even our ethics research has changed. Most of us now have new research projects that relate directly to COVID19. Hopefully this is also fair in relation to all the other important ethics research topics that we now seem to be suddenly losing sight of.

The postponement of this year's EACME conference has been very, very sad for us. We had planned to meet in Rumania, Cluj-Napoca, in September ("Smart Ethics") and then, with a heavy heart, we had to postpone this conference until next year. We would like to thank the local organizer Prof. Maria Aluas for her great flexibility and her courage to easily postpone the conference until next year. Thanks Maria (hope it works out next year!)

So now for this year. Our Secretary General Ruth Horn has made an effort to organize a nice and manageable virtual conference for us all. This virtual conference will take place **September 11, 2020 from 13:00-15:00 (CET)**. After some opening remarks, announcements and prize ceremonies we will turn to the following intriguing academic content: “Ethics in pandemic times: EACME and Covid-19 responses”:

- 13:55 Solidarity in times of a pandemic: What do people do, and why? A comparative and longitudinal qualitative study in nine European countries. **Barbara Prainsack**, Centre for the Study of Contemporary Solidarity, Vienna.
- 14:10 Being an ethics advisor to the UK Scientific Advisory Group for Emergencies (SAGE). **Michael Parker**, Ethox and the Wellcome Centre for Ethics and Humanities, Oxford.
- 14:25 Being an Ethics advisor at Zorgnet-Icuro (organisation of healthcare institutions in Flanders). **Yvonne Denier**, Centrum voor Biomedische Ethiek en Recht, Leuven.
- 14:40 Clinical ethics support in times of pandemics. **Federico Nicoli**, Center for Clinical Ethics Varese, **Bert Molewijk**, Amsterdam University Medical Center.

As EACME members please note that after the academic program at **15.30 our General Assembly** will take place. It would be important that as many centres as possible are represented, because we have to pass

some forward-looking decisions about the composition of the board. And, please note: We will send the Zoom links one week before the meetings.

So we will all "see" each other on September 11th.

Until then, all the best and stay virus-free, yours

Rouven

On behalf of the EACME bureau Ruth, Bert and Angelique.

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ARE COVID-19 IMMUNITY PASSPORTS LIKE DRIVERS' LICENCES? A CRITICAL VIEW

Are Covid-19 immunity passports like driving licenses? Govind Persad and Ezekiel Emanuel have taken this view in a JAMA Network Viewpoint (<https://jamanetwork.com/journals/jama/fullarticle/2765836>). Their paper was intended to calm a heated debate. If immunity passports are comparable to driving licenses, they could easily be classified as ethically safe. Some people have a driving license and others don't. So why bother?

Yet, from an ethical point of view, this comparison is dangerous and misleading. The holder of a passport is entitled to civil liberties in the respective country: of speech, assembly, movement, choice of occupation, and many more. These civil liberties are constitutional rights for each and every one (EU Charter of Fundamental Rights <https://fra.europa.eu/en/eu-charter>). This is why we are all equal. We do not have to justify our being free and equal. It is the state which has to justify the deprivation of liberty imposed on us. Immunity passports would turn this upside down: civil liberties would become privileges only some people enjoy. Individuals who tested positive for SARS-CoV-2 antibodies "would receive certificates allowing them to return to work and potentially to participate in a broader range of activities without social distancing", as one proponent puts it (D. Hemel, <https://papers.ssrn.com/sol3/papers.cf>).

Thus, without an immunity passport, your right to assembly, movement, free choice of occupation etc. would be denied. You could only change this by getting infected and thus risking death. It is important to understand the significance of civil liberties in this case and the ramifications of implementing a policy based on the concept of driving licenses. Driving licenses regulate just a *means* of movement, not the *freedom* of movement. For a number of reasons, some people can't

be allowed to operate a motor vehicle. Yet their right to freedom of movement is not and must not be compromised. To the contrary, this is precisely the reason why democracies take care of public transport, and why persons with conditions that impair driving have a right to barrier-free transport systems. Some might ask whether this terminological battle is worth fighting. In some cities, "passports", such as "Kids Museum Passport", simply refer to cards that qualify you for free or discounted admission to certain venues. In this case, so the argument could go, no one thinks one is talking about passports that restrict civil liberties. Right. But, this example perfectly illustrates the dangerous and misleading effect of the analogy. Speaking of a "passport" in the context of a museum is just a metaphor indicating a special offer; anyone without such a "passport" could still enter the museum by just buying a regular ticket. In contrast, in the case of Covid-19 immunity passports, the scope of permissible activities would correspond to a number of fundamental liberties which would only be accessible for the holder of the document. The holder would (not) be allowed to leave the house, choose where to go, whom to see, and the kind of work they'd like to do. This is much more significant than enjoying a special museum discount.

Equating immunity passports with driving licenses amounts to trivializing the problems of the current Covid-19 pandemic. It is not about dispensing privileges, it is about safeguarding basic rights. Pandemics have always been a danger to basic rights. Ethicists should be aware of this risk, and precise in their examples and wording.

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<https://egmed.uni-goettingen.de/en/start/>

COVID-19 AND MEDICAL ETHICS IN ENGLAND

COVID-19 has sadly had a considerable impact in the UK, and England in particular. According to the WHO, the UK tragically has not only the highest number of deaths in Europe to date, but also the third highest number of deaths globally, behind the USA and Brazil.

Although it came later than some hoped, national lockdown began on 23 March. Vowing to "follow the science", the Government rapidly created new "Nightingale hospitals" to help tackle any increase in need for intensive care, and unprecedented economic

measures were also introduced to help ameliorate the financial impacts of the pandemic.

But the news was not all good. In the ensuing months, comprehensible slogans like “Stay Home, Protect the NHS, Save Lives” unfortunately gave way to more opaque injunctions to “Stay Alert”; the Government’s commitment to “following” the science shifted to being “guided by” the science; and rules that much of the public followed – at great cost to themselves and their loved ones – were reportedly flouted by politicians, scientific and political advisors.

The predicted triage problem thankfully did not materialise, but at least steps had been taken to ensure that there would be adequate intensive care provision. Elsewhere, there have been complaints of a lack of provision and preparedness. Alongside concerns about the adequacy of testing and tracing measures, there have been calls to better protect those in care homes, those from black and ethnic minorities, and indeed health and social care professionals, who have sometimes lacked adequate personal protective equipment (PPE). By early June, the lockdown was easing but, at the time of writing, local outbreaks and lockdowns are occurring in England, and the prospect of another national lockdown has not been ruled out.

Despite this troubling background, professionals and others working in health and social care have remained committed, compassionate, and united. Staff have diverted to new roles in new settings; new ways of working, including remote consultations, have quickly been adopted; and researchers have collaborated on treatments and vaccines, supported by generous new funding initiatives.

There are, inevitably, numerous ethical dimensions to the pandemic and the UK’s response to it. The ethical tensions are considerable: in so far as the two are separable, where should the balance fall between protecting health and protecting the economy? And, more specifically in terms of medical ethics, what balance should be struck between considerations of clinical ethics and those of public health ethics? During a pandemic, autonomy, liberty, and individual welfare will – and have – come into conflict with communitarian concerns to protect the public, so which concerns should be dominant, and when?

In the UK, national ethical guidance for health and social care has – commendably – been issued, which has sought to navigate these tensions, but its authority varies, and the field has unfortunately appeared cluttered and confusing.[1],[2] Against this backdrop, medical ethicists have lamented the lack of clear, co-ordinated, transparent, and consistent ethical leadership.[3] Clinical guidance has also been

contested, and even legally challenged, for alleged failures adequately to account for the rights and interests of, for example, those with disabilities.[4]

However, the UK medical ethics community has not only reacted critically to developments but has also mobilised constructively. Working with various stakeholders, medical ethicists have sought to address some of the ethical challenges, in an effort to support professionals and, of course, patients, service users, and their loved ones. Research into the ethical ramifications of the pandemic is under way: for example, a team from the Centre for Ethics in Medicine in Bristol (working, alongside collaborators, on a rapid project funded by the University’s Elizabeth Blackwell Institute) is seeking to distil and clarify the key messages emerging from the various guidance, which it hopes to publish soon.[5]

The expansion of clinical ethics support services has been another positive development, which signals that ethics should remain at the heart of health and social care. New local and regional committees have been created, which should help to enhance clarity, consistency, and transparency in decision-making. Some of these groups have (again, commendably) sought to ensure that their work is informed by the views of diverse stakeholders.[6] There will still be work to do in this area, a point reinforced by a recent ruling, which emphasises that clinical ethics services should be informed by not only clinicians, but also patients.[7] However, these are encouraging developments, on which the UK can hopefully continue to build.

There have, then, been glimmers of hope and considerable efforts to help during the pandemic. In fairness to all concerned, this is a global crisis for which few could have been fully prepared. Although there have been failings and there is more work to do, the UK has also made some welcome efforts to tackle the crisis. An inquiry may be anticipated,[8] but we should not only look backwards, but also forwards. Ethical challenges still lie ahead, for example, regarding tracing, vaccination, and the restoration of suspended healthcare services. To meet these challenges, we need to plot an “ethical roadmap”,[3] to which medical ethics – in the UK and far beyond – can hopefully continue to contribute.

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COVID-19 OUTBREAK AND PRIVACY: OLD CHALLENGES AND NEW LANDSCAPES

The COVID-19 emergency has overwhelmed healthcare systems' preparedness all over the world, leading to a collective effort in the attempt to find effective solutions to control the spreading of the virus while facing the risk of imbalance between the real clinical needs of the population and the effective availability of intensive resources without significant waste of them.

During this emergency a huge amount of Personal Health Data (PHD) has been produced and collected worldwide for diagnostic reasons, and these data represent a great opportunity to move beyond the use

of population-level data just for simple descriptive epidemiology, to making use of it for causal inferences about COVID-19 outbreak. This raises new challenges but also familiar issues of ethical impact, including data access, privacy, and consent. Privacy norms and expectations are becoming more and more differentiated and stretched in opposite directions by opposing trends. On the one hand, sharing is common in an era of online communication and social networking sites, while, on the other hand, there may be an increased desire for attention to privacy as a result of adverse media events.

New challenges may be raised in the use of PHD for different purposes which can be identified as: data ownership, data access for diagnosis and research, privacy, informed consent, research methods and data quality, and issues related to an evolving ecosystem of devices, apps, and other services that leave "digital footprints" that may be used, for example, in the reconstruction of the contacts of the infected subjects and of the possible contagions.

Although it seems that citizens expressed concern about defending their privacy, they also conveyed considerable willingness to have their PHD shared with and used by researchers, despite a widespread concern related to the possible commercial uses of their PHD, that constitute an arduous task due to regulatory and legal constraints in this topic. It is important to highlight that the necessary procedural mechanisms for data protection and the use of technology software and bio-statistical solutions to facilitate their secure use and transfer across borders must be implemented more broadly by the global research community.

In our societies the concepts of altruism, solidarity, and of research databases as global "public goods" to promote data sharing are differently interpreted. Building trust so that individuals will understand all the efforts made in clinical and epidemiological fields, is essential in ensuring progress in research. Society should recognize its role in this process and take steps to protect citizens against the possible misuse of their information. This will require rapidly-updated governance mechanisms that operate at a meta-level to enable accountable and responsible research. Furthermore, it is important to develop approaches to foster trust related to specific contexts with which research will interface, including, for example, industry and health-care management.

For this purpose, it became important to create the right contractual language and appropriate material transfer agreements, that satisfy both researchers and companies. Policies and practices relating to PHD privacy protection that emerged in the era of medical records, clinical trials, and periodic public health surveys, may be insufficient at this time when more and more PHD are being produced for diagnostic and epidemiological reasons. In fact, there is a need for new technology and policy solutions that simplify data

movement between researchers in different countries, allowing individual rights to be respected while providing access to high-quality and relevant PHD for diagnostic and research purposes. In this way, it will be possible to balance open science with intellectual property, and enabling productive and mutually beneficial collaborations between the private sector and the academy.

Users of self-tracking technologies are frequently unaware of the details of data access to which they agree in the context of clicking “accept” to terms of use. Even with an awareness of data access issues and consent, it is often difficult to predict the effects of these individual choices on privacy. For example, while data may be anonymized before being shared, there is the risk of revealing a person’s identity if two or more sources of personal data are combined.

Several activities that specifically address recommendations about how to handle privacy issues for PHD might help to protect the availability of these forms of data for research aimed at improving the public good, which could be violated in the name of a global emergency upsetting the perception of security itself. Obviously, additional research would be needed to help unpack and understand user expectations regarding their PHD privacy, even in a global emergency scenario. Furthermore, there is a need to develop appropriate education and the spreading of outreach materials to help in discussions on the challenges of digital anonymity. Finally, tools need to be developed to enhance user control of personal data, awareness of sharing, and notification of findings derived from the use of PHD in research. These are essential conditions for establishing the trust needed to assure that data are fairly managed.

The public health response to COVID-19 is based on preventive measures and population surveillance, including social distancing, travel restrictions, prompt reporting of cases to public health authorities, isolation/quarantine, and contact-tracing, which are necessary in identifying disease clusters, mapping the spread of the disease, understanding the pattern of contagion, monitoring trends and, in the end, bringing the spread of the infectious disease under control. These strategies, undoubtedly contrast the individual liberty with the purpose of protecting public health causing a limitation of the individual’s right to privacy, that can be justified if a legitimate public health goal can be achieved by making personal information public. In other terms, it can be said that privacy rights of individuals are sacrificed with the purpose of the common good.

In this context, the way such interventions are introduced and managed is also ethically significant. For example, the state should minimise as much as possible the level of intrusion in people’s private lives and choices (more intrusive measures should not be applied if there are less intrusive means with the same

effectiveness) and it should guarantee that every intervention is proportionate and effective to the goals that it is intended to achieve, providing clear and trustworthy evidence for this; such an evidence-based justification is essential in order to maintain people’s trust in the authorities and to guarantee the compliance with the preventive measures imposed.

The acceptance of the preventive measures from the population requires the state to minimise as much as possible the level of intrusion into people’s private lives and choose, if available, equally effective but less intrusive means. It should also be guarantee that every intervention needs to be proportionate and closely tied up with the goals that it is intended to achieve, providing clear and trustworthy evidence for this. An evidence-based justification is indeed essential in maintaining people’s trust in the authorities and to guarantee their compliance with preventive measures.

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DISABLISM IN A TIME OF PANDEMIC: SOME THINGS DON'T CHANGE

A review by Angela Krenger of a comment by Jackie Leach Scully, IJFAB Blog, April 1, 2020

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The Covid-19 pandemic was accompanied by intense bioethical discussions about the question of how to allocate Health Care resources when there is not enough for everyone in need. This led to a focus on the ethics of triage. In her blog entry, Jackie Leach Scully offers a thoughtful contribution to the crucial issue of allocation decisions, raising awareness of the situation in which people with disabilities find themselves, and providing valuable suggestions for creating better guidelines for clinical decision making.

Jackie Leach Scully points out, that during the pandemic the wish among healthcare professionals for guidance on how to make decisions in the most morally justifiable way and the need for patients, families and the public to know how such decisions are taken are particularly important. In situations of clinical care triage, though, people with disabilities are endangered by disablist assumptions and discriminatory norms.

First, disability is often seen as an impairment of health. However, disabilities are complex and simplifying their diversity is inaccurate. As the primary decision-making criterion in a situation of triage is typically the use of probable clinical outcome, ignoring that diversity constitutes an especially serious matter. Second, Scully reports that most people without disabilities tend to take it as given that disability leads to life being worse. Triage guidance that draws on assumptions about quality of life, thus risks to codify beliefs that people with disabilities "cannot actually enjoy their life like that". Third, she raises concerns about considerations rooted in an idea of the social utility a person will have for society, if saved.

Jackie Leach Scully discusses guidelines of the UK National Institute for Health and Care Excellence (NICE) which were based on a so-called Clinical Frailty Scale (CFS) to illustrate the discriminatory aspect of norms. She concludes that the original guidance showed a worrying lack of awareness that norms are not universal; that a lot of people who do not fit the social norm of the independent ability to dress, to move and so on, are nevertheless healthy and lead a prosperous life.

In order to construct better guidelines, Scully recommends that guidance for critical care should always include explanations for the decision criteria it suggests and that it should not use disability status as a proxy for health status. She highlights that clinical decisions should always include knowledge about individuals. Also, guidance should exclude considerations of broad social utility and openly admit that disabled people are to be treated equal to everyone else.

Jackie Leach Scully is Professor at UNSW in Sydney.

Profile: <https://research.unsw.edu.au/people/professor-jackie-leach-scully>

Blog: <https://www.ijfab.org/blog/2020/04/disablism-in-a-time-of-pandemic-some-things-dont-change/#comments>

¹ SIAARTI (2020) Clinical ethics recommendations for the allocation of intensive care treatments, in exceptional, resource-limited circumstances, Version n. 1 Posted on March, 16th – 2020

<http://www.siaarti.it/SiteAssets/News/COVID19%20-%20documenti%20SIAARTI/SIAARTI%20-%20Covid-19%20-%20Clinical%20Ethics%20Reccomendations.pdf>, [07-08-2020]

² Deutsche Interdisziplinären Vereinigung für Intensiv-und Notfallmedizin (DIVI) weiterer Fachgesellschaften und der Akademie für Ethik in der Medizin (AEM) 25.03.20
Entscheidungen über die Zuteilung von Ressourcen

DECISION MAKING IN THE CONTEXT OF THE CORONA PANDEMIC AND THE DISABILITY PERSPECTIVE

Decision-making in the context of the corona pandemic and the disability perspective

In March 2020, images of overcrowded hospitals and intensive care units, especially from Lombardy in northern Italy, shocked many people. In addition, there were indications that in Italy but also in Alsace, people infected with COVID19 would no longer receive intensive medical treatment or ventilation beyond a certain age. The scarcity of resources and allocation problems no longer seemed abstract, but very concrete.

The Italian medical association SIAARTI stated quite early "An age limit for the admission to the ICU may ultimately need to be set. The underlying principle would be to save limited resources which may become extremely scarce for those who have a much greater probability of survival and life expectancy, in order to maximize the benefits for the largest number of people."¹ Subsequently, medical societies in various European countries published corresponding recommendations.

The following article examines the situation in Germany, focussing on the public discussion on the recommendations of the Deutsche Interdisziplinäre Vereinigung für Intensiv-und Notfallmedizin (DIVI), other medical societies and the Academy Ethics in Medicine on the allocation of resources in the corona pandemic.² This discourse was shaped by members disability activists and disability organisations.

Patient-centred decision-making

Treatment measures are permissible under the following two conditions: 1. According to the treating physicians, there is a medical indication for starting or continuing a treatment and 2. this is the patient's will.³ A medical treatment is indicated if it increases the patient's* chance of surviving a disease, possibly improving his/her condition, avoiding or retarding a deterioration. In the case of particularly invasive measures, other aspects are considered such as side effects, possible complications,

in der Notfall- und der Intensivmedizin im Kontext der COVID-19-Pandemie-, Klinisch-ethische Empfehlungen <https://www.divi.de/empfehlungen/publikationen/covid-19/1540-covid-19-ethik-empfehlung-v2/file>, [07-08-2020]

³ DGIIN and DIVI (2020), Empfehlungen zur intensivmedizinischen Therapie von Patienten mit COVID-19 S1-Leitlinie Stand 19.06.2020 (Version 2) p17 https://www.dgiin.de/files/dgiin/leitlinien/20200619_S1-Leitlinie_Empfehlungen-intensivmedizinische-Therapie-COVID-19.pdf, [07-08-2020]

or an expected burden on the patient. It is not easy to provide a clear indication, especially under these circumstances. Recommendations and guidelines from professional associations should support doctors in their decision. The following parameters play a role in the decision about admitting COVID-19 patients to the intensive care station (including hypoxaemia, respiratory rate, blood pressure, elevated lactate levels).⁴

The medical indication given is a necessary but not sufficient condition. The patient decides whether an indicated therapy should be used in his/her specific case.

Discussions on prioritisation and rationing in the health care system

While the decision-making process described above is patient-centred, there has been a discussion for many years whether and if so, in which situations superior aspects as scarcity of resources may or must also be considered.⁵ In Germany unlike in other countries, discussions about prioritization or rationing in the health care system do not play a significant role.⁶ Furthermore the term triage has until now been used rather cautiously in the German-speaking countries.⁷ It originates from the military or disaster medicine and is, according to the Duden; the "classification of the injured (in a disaster) according to the severity of the injuries."⁸ In the course of the Corona pandemic, however, it is used in numerous papers, statements and articles. Nobody asks whether the decision-making situation in hospitals in a situation of resource scarcity is comparable to that of catastrophes.

Measures to avoid resource shortages in times of corona pandemic

In fact, much has been and is done in clinics to avoid situations where patients would be rejected, would not be given intensive care despite medical necessity, or would not be connected to a respirator. The number of intensive care beds and respirators has been increased to a great extent and operations have been postponed. In addition, a central register on the capacity of intensive care beds in acute care hospitals was installed.

The clinical-ethical recommendations of DIVI and others

⁴ DGIIN and DIVI (2020), see above p. 3ff

⁵ Winfried Krug (2010) 39. Symposium für Juristen und Ärzte Juristen und Ärzte referierten und diskutierten am 19. und 20. Februar 2010 in Berlin über „Engpässe der medizinischen Versorgung – Rationierung – Allokation – Triage“ https://www.slaek.de/media/dokumente/04presse/aerzteblatt/archiv/2001-2010/2010/04/0410_179.pdf, [07-08-2020]

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⁷ „Triage“ in der Notaufnahme <https://pflege-professionell.at/triage-in-der-notaufnahme>

⁸ Duden <https://www.duden.de/rechtschreibung/Triage>

⁹ <https://www.divi.de/aktuelle-meldungen-intensivmedizin/covid-19-empfehlungen-zur->

Meanwhile DIVI, other medical societies and the Academy for Ethics in Medicine, developed clinical-ethical recommendations and presented them for discussion.⁹ They describe various situations of resource scarcity where it is imperative to limit the "otherwise necessary patient-centred treatment decisions". In the most extreme situation, there are "no intensive care resources, no resources in the emergency room, no other accessible resources " The "enormous emotional and moral challenge for the treatment team" is acknowledged the decision situation on "limited resources" is compared with that of "triage in disaster medicine."¹⁰

The recommendations aim at contributing to the "best possible" use of available medical resources. Therefore, the "achievable" prognosis for a patient is the benchmark for allocation. Various factors should be included in the overall assessment as the severity of the disease, the general state of health, comorbidities that may worsen the diagnosis (e.g. advanced cancer or immunodeficiency).¹¹

The principle of chance of success it also applied in the distribution of organ transplantation.¹² In addition the Transplantation Act lists urgency as a principle. (§12 Law on the Donation, Removal and Transfer of Organs and Tissues (Transplantation Law - TPG). Due to the Marckmann, one of the authors of the recommendations, this principle cannot be applied in the case of resource scarcity as admission to intensive care would be vital for all patients. Hence, the principle of urgency would not be adequate to discriminate between patients.¹³

It is recommended to establish a ranking between all patients with a need for intensive care measures, i.e. not only between patients suffering from Covid 19. If necessary, i.e. if this may improve the chances of survival for others, it should also be possible to stop artificial respiration of patients¹⁴.

Decisions should be based on the multiple-eye principle, so there should be joint decision-making by at least two intensive care physicians and an experienced member of the nursing team.

[intensivmedizinischen-therapie-von-patienten-veroeffentlicht_07-08-2020](#)

¹⁰ DIVI et al. (2020) Klinisch-ethische Empfehlungen Entscheidungen über die Zuteilung von Ressourcen in der Notfall- und der Intensivmedizin im Kontext der COVID-19-Pandemie divi, 2. Version

¹¹ cf. Uwe Janssens 2020, Webinar "Triage - wer wird behandelt, wer nicht? Am 24.04.2020, transcript, not authorised https://gruene-europa.de/files/doc/docs/890899b2c778046003cc2b419e8912_b3.pdf, [07-08-2020]

¹² cf. Georg Marckmann 2020, webinar, see above

¹³ cf. Marckmann 2020 see above

¹⁴ DIVI et al, see footnote 10

The clinical-ethical recommendations of the DIVI and others describe situations where unconditionally everybody hopes they will never occur. At the same time, it should be as concrete and "practicable" as possible.¹⁵ The critique of the Recommendations from the perspective of people with disabilities

To the surprise of the authors of the recommendations, people with disabilities and organisations of people with disabilities also took part in the discussion.¹⁶ In fact, when drafting the paper, the authors did not have people with disabilities in mind but rather older people. An important aim was to find a differentiated approach to avoid discrimination based on age by including different factors.¹⁷

However, it is precisely this enumeration of comorbidities that causes the critique because it is viewed as discriminatory towards people with disabilities. In addition, people with disabilities raise their voice and express their fear. Especially people with neurological pre-existing conditions, being listed as one of the comorbidities, are worried that they will be denied the best possible care in case of corona infection and that their options for therapy will diminish. They justify their concern with negative personal experiences with the health care system. In a webinar participants gave examples of having been "given up several times" but still living. One gave the example that doctors not knowing her are willing to administer incompatible drugs as they mistake her disease with another one.¹⁸

From the disability perspective it is also problematic to use the clinical frailty scale. While it is generally applied for people over 65 there is no reference in the recommendations to the age limit. People with disabilities fear the scale might be used in their case thus causing a disadvantage for them. In addition, a flow chart is provided in the recommendations. It is firstly criticised that this might prevent an individual assessment. Secondly the depiction of the wheelchair in the flow chart

is seen as problematic as it might strengthen the association with people with disabilities.

Due to the Forum behindeter Juristinnen und Juristen (Forum of Disabled Lawyers) it is fundamental that "patients who can be treated with a chance of success must be given "equal opportunities". According to them the following principles would ensure this goal: the priority principle, the urgency principle and the random principle.¹⁹ They call for clarification by the legislator as such far-reaching decisions should not be made by professional associations alone. In July, nine people with disabilities filed a constitutional complaint on the basis of the lack of legal basis.²⁰

The Federal Government Commissioner for Disabled Persons, Jürgen Dusel, demanded a revision of the recommendations. Clarification would be needed so people with disabilities would not be excluded from treatment due to pre-existing conditions "if a decision has to be made on the distribution of resources." He also called for a debate in the Bundestag on the criteria that should be used in to decide which Covid-19 patients should continue to be treated when hospital capacities are limited.²¹

Reaction to the criticism of people with disabilities

DIVI, the other medical societies and the Academy Ethics in Medicine revised the recommendations and published it as S1 guideline.²² "Among other things, we have made it clearer that underlying diseases and disabilities are not legitimate criteria for triage decisions. In addition, the examination of the patient's will prior to admission to the intensive care unit was given more emphasis".²³ The clinical frailty scale and criteria such as multimorbidity remain in the revised version. The goal was: "to minimize the number of avoidable deaths caused by resource scarcity. The decisive criterion for an inevitable prioritization remains the clinical success rate of the

¹⁵ DIVI (23.4.2020) Triage bei COVID-19: „Wir entscheiden nicht nach Alter oder Behinderung“ – Intensiv- und Notfallmediziner aktualisieren klinisch-ethische Entscheidungsempfehlungen

<https://www.divi.de/presse-meldungen-nach-themen/200423-presse-meldungen-divi-aktualisierung-ethik-paper/viewdocument/3816>, [07-08-2020]

¹⁶ AbilityWatch, Achse, Deutsche Gesellschaft für Muskelkranke, Liga Selbstvertretung, Interessenvertretung selbstbestimmt leben

¹⁷ Georg Marckmann, 2020, see above.

¹⁸ N.N. 2020 in webinar, see above

¹⁹ FbJJ Forum behindeter Juristinnen und Juristen (2020) Stellungnahme zu den Empfehlungen der Fachverbände für den Fall einer Triage authors: Nancy Poser und Arne Frankenstein

https://www.teilhabe-gesetz.org/media/Ottmars_Dateien/200406_FbJJ_Stellungnahme_Triage.pdf

²⁰ Oliver Tolmein, 2020, Verfassungsbeschwerde gegen Triage Kanzlei Menschen und Rechte

<https://www.menschenundrechte.de/de/blog/details/artikel/verfassungsbeschwerde-gegen-triage-1374.html>, [07-08-2020]

²¹ Jürgen Dusel (2020) in epd 2020 Behindertenbeauftragter für Bundestagsdebatte zu Corona-Behandlungen <https://www.evangelisch.de/inhalte/168891/17-04-2020/behindertenbeauftragter-fuer-bundestagsdebatte-zu-corona-behandlungen>

²² DIVI 23. 04.20 press release: Triage bei COVID-19: „Wir entscheiden nicht nach Alter oder Behinderung“ – Intensiv- und Notfallmediziner aktualisieren klinisch-ethische Entscheidungsempfehlungen <https://www.divi.de/aktuelle-meldungen-intensivmedizin/triage-bei-covid-19-wir-entscheiden-nicht-nach-alter-oder-behinderung-intensiv-und-notfallmediziner-aktualisieren-klinisch-ethische-entscheidungsempfehlungen>, [07-08-2020]

²³ S1 guideline summarises recommendations for action by experts. However, the knowledge is not systematically compiled and evaluated. S1 guidelines are therefore not very reliable. <https://www.gesundheitsinformation.de/was-sind-leitlinien.2980.de.html>

intensive care treatment - i.e. the probability that the patient will survive the intensive care treatment. This is intended to minimise the number of avoidable deaths caused by the scarcity of resources.

The discourse during the webinar "Triage - wer wird behandelt, wer nicht?"²⁴ highlights underlying problems in the communication between doctors and people with disabilities. There was understanding for their fear but a lack of concern for their concrete negative experience with the health system. Instead, they audience was urged to have confidence in the proposed decision-making procedures.

What situations are we talking about?

So far there are few concrete ideas about the situations in which decisions are (should be) made in hospitals in case of extreme situations (see above). Is it really a situation of a catastrophe where a decision should be made very quickly about the treatment or non-treatment of people? This would be the case, for example, if at the same time numerous COVID 19 patients were waiting in front of a hospital without another hospital being able to admit them in the foreseeable future. But even under these circumstances if they do not require immediately artificial respiration, an examination would be necessary, because only then could it be clarified whether admission to the intensive care unit is necessary/essential for them.

When COVID 19 patients have already been admitted to the hospital, several hospital staff would meet at certain intervals to make the necessary decisions. The question is whether the alternatives would really be as clear-cut as in the following example, in which on the one hand a 75-year-old patient with comorbidities dies after being treated and ventilated in the intensive care unit for 6-8 weeks, while five people die who would have survived with one week of ventilation.²⁵

The basic problem: despite all the efforts of doctors to make a realistic assessment of the chances of success, it can only be determined ex post whether the assessment was right. Thus, it is less likely, but not impossible, that the 75-year-old patient would have survived after 6 weeks, and that one or more of the five people would have died even with ventilation. In fact, the likelihood of survival if ventilation is required decreases with age.²⁶ But it is nearly impossible to predict to which group the patient belongs - whether to the larger group of those who die or the smaller group of those who survive.

²⁴ See footnote 11

²⁵ cf. Uwe Janssens 2020 see above

²⁶ Joint press release of WiDO, DIVI and TU Berlin Berlin, 29 July 2020 Approximately one fifth of hospitalized COVID-19 patients died First national analysis for Germany based on

The uncertainty of prognosis also exists with a patient-centred approach. In the case of an allocation situation, however, there is the additional ethical problem that the number of human lives would possibly be weighed against each other and that, as provided for in the guideline, people would be taken off the ventilator, which, according to some criminal law experts, corresponds to the offence of killing.²⁷

Instead of weighing up the chances of success of different people, it would have to be analysed regularly whether the situation is still the most extreme (see above) or whether there are alternatives in neighbouring or even distant hospitals. After all, patients from Italy and France were also treated in German hospitals. From my point of view, it would be wise to avoid the term triage as it is basically used for situations where there is little/no time for reflection and is usually associated with a dilemma situation.

The discussion makes it clear how important it is to avoid situations where patients would be rejected by hospitals, would not receive intensive care despite medical necessity or would not be connected to a respirator. The past months have shown possibilities for action for the state and society. If the state were to set up criteria according to which decisions should be made in the event of a shortage of resources, it would at the same time legitimize failure.

One rationale for the DIVI's recommendation is the understandable desire to give doctors and nurses in an extremely problematic situation at least a certain degree of security. To avoid age discrimination, the authors of the recommendation established criteria that should be considered when assessing the chances of success. It is precisely these criteria, however, that are now leading to concrete concerns on the part of people with disabilities that they are not being adequately cared for. Thus, recommendations intended for hypothetical situations in the future have negative consequences in the present.

For the reasons given above, it is doubtful that the desired level of safety can be achieved. Therefore, consideration should be given to reducing the recommendations to a procedure in which the multi-eye principle is described and where it is ensured that those involved in the decision-making are called upon to look for alternatives regularly.

Disability Mainstreaming and Participation

The discussion on the DIVI-recommendation and guidelines shows how little the perspective of people with disabilities is considered in the health care system. It is not possible to know if the recommendations/guideline would have been different with an early participation of

completed hospital cases <https://www.divi.de/joomlatools-files/docman-files/presse-meldungen-nach-themen/covid-19/200729-divi-press-report-covid-19-analysis.pdf> ,[07-08-2020]

²⁷ Oliver Tolmein (2020) see above

disabled people. Irrespective of this, it seems imperative to implement Article 25 of the UN Convention on the Rights of Persons with Disabilities as soon as possible. It describes their right to enjoy the highest attainable standard of health without discrimination on the basis of disability. In order to achieve the goal it is required for "...health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;" (CRPD, Article 25 d)

Already at the beginning of the 21st century, the question of how to take into account disadvantaged groups or groups disproportionately affected by pandemic preparedness, pandemic responses and the pandemic itself was discussed at the international level on the basis of social justice. The starting point was the Bellagio Statement²⁸, which recommended identifying these groups, involving them in planning processes, and taking their particular needs into account in recommendations and policy measures^{29 30} Disability Mainstreaming and participation should apply not only to political measures, but also to guidelines of medical societies.

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SOME PERSONAL EXPERIENCES OF TREATING COVID-19 PATIENTS

Lukas Balsiger and Rouven Porz

Dr. Lukas Balsiger is a young 28-year old Swiss resident, who finished his medical exams only three years ago. Now, in spring 2020, he was confronted with the corona crisis in the intensive care unit of a medium sized hospital in Switzerland. For all of us, this year was a big challenge, but I (Rouven Porz) asked myself: how does a young medical doctor deal with the fact that this is the start of his professional career? What do these questions mean

²⁸ Bellagio group (2006) BELLAGIO STATEMENT OF PRINCIPLES
https://www.unicef.org/avianflu/files/Bellagio_Statement.pdf

²⁹cf. Uscher-Pines, Lori; Duggan, S. Patrick; Garron, P. Joshua; Karron, A. Ruth; Faden, R. Ruth (2007): Planning for an Influenza Pandemic: Social Justice and Disadvantaged Groups The Hastings Center Report , Vol. 37, No. 4 (Jul. - Aug., 2007), pp. 32-39 Published

for him medically-speaking, and what ethical challenges did he face? Let's listen for ourselves:

(1) Lukas, tell us how it all started? When did you treat your first COVID19 patient?

When the first patients with COVID were diagnosed in Switzerland and we started treating cases in our ICU, I was on holiday. During my last days of holiday I knew that upon my return – everything would be different. We already knew that all of our planning had changed and that we would have to stay available at short notice because at the time we were very concerned about colleagues getting infected. It is also the first time that a boss told me to really relax on my days off and sleep well. Luckily nobody in our team got infected.

(2) An intensive care unit is always full of existential challenges. What was different about COVID19 patients?

At the beginning we did not know anything. We had some data from Chinese hospitals but a lot was unknown. It was challenging and interesting to live through fundamental changes in treatment protocols at such a rapid rate. What was valid one day was invalidated the next. Luckily for us and our patients we were very well connected with ICUs in France and Italy with more experience.

(3) From a medical point of view: did you have experiences that you did not expect in your professional life?

One thing was the sheer impossibility of anticipating the outcome of individual patients. Linked with that uncertainty was the question how to talk to the families of patients regarding prognosis.

Furthermore, it was very humbling to have no real idea or experience with the situation that could help. And often, nobody could give a scientifically well approved input or an input based on larger experience – no senior staff, no specialists. That was new. It was a good experience because through not knowing, the culture of shared decision-making grew which I really appreciated. There were long and sometimes difficult discussions – but we were in the discussions together.

(4) From an ethical perspective: What challenges did you face?

by: The Hastings Center Stable
<http://www.jstor.com/stable/4625761> [17.06.2020]

³⁰ cf. Grüber, Katrin (2008): Challenging the "Bellagio Statement on Social Justice and Influenza" – and the Perspective of Disabled People, paper on the symposium „Les enjeux d'éthiques de la préparation à une pandémie de grippe au sein de l'Europe
https://webgate.ec.europa.eu/chafea_pdb/assets/files/pdf/20084154/20084154_d0_1-19_oth_en_ps.pdf [17.06.2020]).

In the ICU the allocation of resources at the very beginning was a difficult topic : will we have to stop ventilating certain patients to free ventilators for patients with better prognosis. Luckily, we never had the situation in our institution.

And, honestly, it was one of the most challenging experiences to see people die alone. And for them to have been alone for weeks before dying because of lockdown and visiting restrictions in the hospital. I always appreciate being there for the families of severely ill patients – and that was simply not possible during a long period of time. We found the solution of video-calls very helpful to give the families an idea of what was going on. Looking at the society, I think that the confrontation with medical science was very challenging. People expected precise answers from medical science and wanted to set them in stone. When they saw that accepted facts change in light of new data people grew insecure and suspicious. I feel the scientific medical community – or especially media that reports it needs to educate society in the nature of medical science. It is completely normal for knowledge to evolve and solutions to problems to change. That is science and scientists aren't afraid to abandon old ideas when new insights are gained. Pure facts that are set in stone do not exist.

(5) What do you hope to be able to say about the year 2020 in 20 years' time?

We do not know today what we did right and what we did wrong – even though some experts like to make us believe they know. For me it's important to have made the best of an unknown situation with the information that was at hand.

I hope we will say that we did many things right. Realizing that this situation is absolutely unprecedented for my generation I am very interested in the things we will have learnt in 20 years. I am eager to look back, criticize – I hope I will be humble enough to accept the criticism. Still, my hope is to be able to look in the mirror and say we did our best according to our knowledge.

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COVID-19 and Italian prisons: the straw that broke the camel's back

In Italy the spread of the Covid-19 pandemic has shined a spotlight on the unsolved problems inherent to the national prison system. The detention penalty has principally three purposes. First, the separation from society and confinement of dangerous individuals in order to guarantee public's safety. Second, by depriving someone of their liberty for a period of time, retribution is delivered in a serious but proportionate way where a certain crime has been committed. This punishment also intends to deter people from committing crimes. Third,

correction and rehabilitation to the community, with the possibility of preparing the prisoner for a law-abiding life. During the Covid-19 outbreak in Italy it was issued the Decree Law No 11 (8 March 2020), which, in order to prevent the spread of the infection in prisons, suspended all visits and the partial-freedom regime. Even if this Decree took into account several compensatory measures, with the possibility that communications between inmates, their relatives and their lawyers could take place either by phone or video-conference, the increase of time available for calls and the chance to make free video calls, the limitations imposed on prisoners by Italian law provoked violent reactions in several prisons. For these reasons, furious riots broke out in several penitentiary institutions in March, costing the lives of 13 inmates. Furthermore, 40 prison officers got injured, in addition to the devastation of built environments and the escape of dozens of prisoners. These riots in Italian prisons have highlighted that something went wrong in the fragile balance between confinement, punishment, and rehabilitation, reminding us that the most serious problem of the Italian prison system is undoubtedly overcrowding. In Italian prisons, in fact, more than ten thousand detainees are held in excess of the regular capacity with an overcrowding of about 129 percent. Additionally, in this overcrowded setting, there is an overrepresentation of drug addicts (some of these detainees, during the above mentioned riots, died from drug overdose, after assaulting the infirmaries to steal methadone), and people who suffer from mental, and physical diseases, like infectious ones. Many of these diseases may be present before admission to prison and may be further exacerbated by the detention's conditions. There is a greater prevalence among detainees of diseases, linked to unhealthy lifestyles and habits, such as high consumption of alcohol and tobacco, use of psychotropic substances, little or no dental hygiene, sedentary lifestyle, unbalanced diet, etc. It has also been demonstrated that the prolonged confinement, with the isolation from the loved ones, the persistent lack of privacy, the lack of meaningful activity, with unbearable uncertainty about future perspectives cause a deleterious effect on the mental health of detainees. Regarding infectious diseases, it is known that the prevalence of HIV, HCV, HBV, and tuberculosis is higher in prison population than in the general population, mainly because of both the criminalisation of drug use and the detention of people who use drugs. Furthermore, the promiscuity and the restricted space intensifies the risk of infectious diseases' spreading. The fact that detainees suffer from poorer health than the general population and bear a substantial burden of physical and psychiatric disorders makes them more likely to be severely affected after being diagnosed with COVID-19. This vulnerability strengthened the importance of preventing Covid-19 outbreaks in prison. WHO/Europe has published interim guidance on how to deal with the coronavirus disease in these settings, entitled "Preparedness, prevention and

control of COVID-19 in prisons and other places of detention". This guidance lists the general precautions for infectious respiratory diseases as observing physical distancing; washing hands with soap and water and drying them with single-use towels; utilizing alcohol hand sanitizer; covering mouth and nose with disposable tissue when coughing or sneezing, and; avoiding touching of eyes, nose or mouth if hands are not clean. It is clear that preventing the importation of the virus into prisons and other places of detention plays an essential role to avoid or minimize the occurrence of infection and of serious outbreaks in these settings. Moreover, as prisons continue to admit and release individuals, the infection could become a threat to public health both within and beyond prison walls. Nevertheless, we cannot ignore that even washing your hands can be tough in prison, because there are lots of people using a small number of bathrooms and it is not always possible to access to soap when you wash your hands. In particular, the conditions of imprisonment in Italian prisons are frequently unhealthy and characterized by lack of space, lack of light and fresh air, lack of clean sanitary facilities or means for personal hygiene. With the purpose to avoid or, at least, contain the spread of the infectious disease in Italian prison, some sanitary procedures have been adopted, including quarantine for new inmates and infected individuals, isolation facilities, the provision of protective equipment for prison staff and the suspension of prison transfers, unless for health or emergency reasons. In order to diminish the number of detainees, it was also introduced the possibility for certain categories of low-risk offenders with less than 18 months to serve – under certain conditions – to benefit from a simplified procedure for home detention. In addition to this releasing policy, an important attempt to improve the conditions of detention was made on May the 19th 2020, when another Decree Law was issued, which allocated 31.7 million euros to the judicial offices and central offices of the Ministry of Justice to allow the sanitation of environments, the purchase of hygienic-sanitary equipment and other personal protective equipment. This Decree also provided that a part of the aforementioned funds was utilized to purchase information technology equipment for detainees. The allocation of these funds could represent a first step towards a greater and more efficient use of technology in prisons. In spite of that, the riots with the consequent public disorder we have witnessed can have profoundly destabilizing effects: the penitentiary system, which has appeared not to be able to guarantee security conditions and public order inside the jail, has showed its worrying fragility, instilling fear in the population, who feel its own safety already threatened by the pandemic and can feel a sort of emotional detachment from detainees' situation, blaming detainees for these dangerous riots. However, when it is more difficult to recognize aspects of humanity in the prisoners' behaviour, we must ask ourselves in what way we failed as a society. In this contest, we should transform the coronavirus pandemic into a window of

opportunity to humanize the conditions of detention, giving detainees the possibility of serving their sentence in a safer and more humane prison. During this tragic period, it's our responsibility as a society to protect disadvantaged people and put in place tangible measures to guarantee that detainees, who already do not have full constitutional rights as the fundamental right to freedom, will not also be deprived of the right to health. When the Coronavirus pandemic is over, society shall have to show it has learnt that detainees deserve more human treatments. While life in Italian prisons is starting to return to normality, with the restart of family visits, even if it is often up to the prison administration to decide how many people will be accessing the prison depending on the circumstances of the facilities, visits from volunteers and other professionals that are not part of prison staff persist suspended. Furthermore, in some cases, the administration has suspended the access to technology for detainees, giving up on the recent achievements about the creation of a different connection between inside and outside the prison. The use of technology could, in fact, be important not only for "private" connection between detainees and their loved ones, but also to improve access to the distance-education world and protect the right to information.

Measures that seek to control the spread of COVID-19, including the reduction in prison population and the enhancement of hygienic conditions, could improve the general health status of this marginalized population. The real challenge is to remember that it is our duty and moral obligation to allow detainees to serve their sentences in a dignified environment, solving the problems linked to the penitentiary system, instead of rapidly returning to look at what society considers more notable than defending the dignity of detainees.

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PUBLIC HEALTH INFORMATION AND COMMUNICATION BARRIERS DURING THE COVID- 19 PANDEMIC

Ethical and practical challenges in providing fair and barrier-free information by example of deaf people and immigrants in Germany

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Ethical debates during the current Covid-19 pandemic have focused mostly on the fair distribution of ventilators, in particular in regard to elderly patients and patients with disabilities. Public and medical discourse, however, has also brought to attention other fundamental ethical challenges, for example how to provide equal and barrier-free access to health care information in diverse societies. Is critical information on how to contain the pandemic really communicated in an appropriate and comprehensible way to all members of society? From an ethical point of view, equal access to healthcare information is a necessary requirement of justice and civic inclusion. In a pandemic, a lack of barrier-free health information is not only an individual risk, but the increased risk of infection for under-informed citizens also endangers public health at large. Fair and equal access to health care information thus is essential for an efficient and safe public health care system, and a fundamental requirement of justice.

Preventative measures can only be successful when all social groups are included and their communication needs are considered. Blind people, for example, need information in non-visual formats, while deaf people need information in visual form, in particular in sign language. People with intellectual disabilities need information in simple language. Ethnic minorities or immigrants need written or oral information in their native language. While it is unrealistic to expect health care staff competency in this entire range of languages and communication modes, it is necessary that they are aware of the negative consequences of communication barriers for different population groups. Thus it is necessary, first, for public health institutions to develop an awareness of these communication barriers and of the societal obligation to provide barrier-free information. Second, it is necessary to develop an infrastructure for providing information in different media and languages that can be used fast and without much bureaucracy, both in a pandemic and beyond.

Good communication needs to be relevant, reliable, and respectful in regard to the needs of different social and cultural groups. Different countries in Europe have approached the provision of barrier-free communication in a variety of ways, and with varying levels of commitment. The German health care system has not always sufficiently considered the diversity of communication needs and sociocultural backgrounds. Even if there is an awareness for diverse communication needs, it is often assumed that they can be met by a one-size-fits-all approach. During the Covid-19 pandemic

influential national organizations such as the *Nationale Akademie der Wissenschaften Leopoldina* have pointed out the importance of providing access to health care information for vulnerable groups (Leopoldina 2020). It defines “vulnerable groups” as those who have little social resources, power or influence in politics and society. The term “vulnerability,” however, needs to be approached critically. On the one hand, it may be a useful indicator for vulnerability to discrimination. On the other, it may lead to a generalized victimization of certain groups. A working group of the *Akademie für Ethik* emphasized that during the current pandemic German public health has not given enough attention to sociocultural aspects of communication and thus enforced such inequalities in German health care.

By example of two groups, we would like to analyze the diversity of communication needs and barriers during the current pandemic, pointing to research gaps and potential solutions: Deaf people who communicate in sign language and immigrants / people from immigrant families. On first glance, these two groups might not have much in common. However, despite their differences there are similarities in their experiences with health care and in the societal disregard of communication needs that are not covered by spoken or written German. Both groups, of course, are not homogenous, but highly diverse in themselves, and have an intersectional overlap, e.g. in deaf immigrants. The latter are multiply disadvantaged in their communication needs. A critical comparison of these two groups can thus provide insights into structural discrimination, sociocultural stereotypes, and their influence on access to health care information. In hospital settings and in consulting with physicians, both groups are dependent on information in their native languages and on professional interpreters.

Native language needs are complex and diverse. People with immigrant backgrounds, in particular of the first generation, are at risk of missing crucial information due to lack of communication in their native language. Often, there are no professional interpreters for their language or dialect. Interpreting by friends, family members, or acquaintances is problematic because of the complexity of medical information. It is also ethically fraught, as lay interpreters are not bound by ethical codes of confidentiality and are part of a patient’s personal environment.

The native language of many deaf people are national sign languages with their own grammar and syntax. In Germany, this is German Sign Language (*Deutsche Gebärdensprache, DGS*) and its dialects. Due to a long history of structural discrimination in education, many deaf people do not have a good command of written German. While the mandatory wearing of masks is a necessary tool in fighting the pandemic, it poses serious communication challenges for deaf people. Sign language requires facial expressions. In German Sign Language in particular, mouthing is important for distinguishing between meanings. Lipreading, too, is

made impossible by masks, yet even without masks, only about thirty percent of the spoken words can be distinguished unambivalently. In medical communication, the resulting misunderstandings can literally be fatal.

A look at the legal framework shows why barrier-free medical information is rarely provided and illuminates important differences in the legal status of both groups. With the 2002 *Gleichstellungsgesetz* and by acknowledging the *UN Disability Rights Convention* in 2009 German Sign Language was acknowledged as a language of its own. It is thus discriminatory to deny deaf people access to sign language. While the disability status of deaf people remains controversial (World Federation of the Deaf 2019), it grants access to barrier-free communication, at least in theory. Immigrants, on the other hand, do have no such legal claim for their languages in Germany.

In reality, however, and in particular in health care, access to medical information and communication in their native language is insufficient for both groups. Although access to interpreters is defined as an essential part of health care, who pays for them remains unclear. Court decisions from the 1990s mandate that in ambulant care, patients insured via public health insurance (*Gesetzliche Krankenversicherung*) have no right to paid interpreter services. Often, family members or community members are supposed to serve as interpreters, which, as mentioned above, poses serious ethical and practical challenges, especially when communicating complicated topics such as virus epidemiology. Currently, even this less-than-perfect solution is not viable. Due to physical distancing rules and risk for infection, individuals are often not allowed to bring along family or community members to health care settings, leaving them without communication assistance.

The Covid-19 pandemic has reinforced these gaps in barrier-free communication, while simultaneously bringing them to public attention. Deaf organizations and activists have pointed out that public health information has only rarely or belatedly been provided in sign language. The media has reported on the difficulty of communication between hearing and deaf people when both sides are wearing masks. These reports have usually focused on lip-reading and have mostly neglected the importance of facial mimic for sign languages.

Despite this lobbying and media attention access to Covid-19 information for deaf people remains a confusing patchwork of different local, regional, and national regulations and provisions by public health institutions and the media. The *Robert-Koch-Institut*, Germany top-most public health institution, marks their documents as “not barrier-free,” thus demonstrating both awareness for the need for barrier-free information and indifference for the people who need such information. Various Corona

telephone hotlines, for example by federal states or local *Gesundheitsämter* (public health offices), only provided information in sign language very late or not at all. An emergency app, equivalent to the national emergency phone service, has been planned for years, but never implemented, leaving deaf people without barrier-free access to emergency services.

As a result of the issues sketched above, deaf people face discrimination in their access to relevant medical information about Covid-19, resulting in higher risk of infection and lack of access to appropriate medical services. The exact extent of regional differences, their consequences and their structural reasons (e.g. because of different attitudes toward sign language in different localities) remains to be examined in cooperation with stakeholders.

Access to appropriate health information for immigrants and from immigrant families during the Covid-19 pandemic as also been insufficient and differing between regions, yet has seen even less public attention. The Robert-Koch-Institut, for example, has started to provide translation of important documents in various languages (Turkish, Arabic, Russian), yet only with a delay of several weeks. *Deutsche Welle*, the German international broadcasting service, offers a news service in 30 languages, including information on Covid-19. It remains to be seen in how far this delayed and insufficient information affects different groups of immigrants. Their position in German health care, the effect of stereotyping, and their attitudes toward health and health care have been a small and rather neglected field of research, although one that has pointed out that this group has not sufficiently been reached by preventative health care programs. One can assume that this is also true in the current pandemic, yet this remains an important topic for future research.

A reason for the lack of attention for health care information for immigrants might be their relatively low degree of organization, especially when compared with that of deaf people. The roughly 80.000 deaf people in Germany share a language, culture, and, identity, and are organized in local, national, and international organizations. These organizations lobby for barrier-free access to health care and simultaneously provide health care information to their members. Since the beginning of the Covid-19 pandemic, they have contributed significantly to making health care information more accessible for deaf people. Immigrants (among which there certainly also are deaf people), on the other hand, are a much more diverse group. At best, they are organized by country of origin or ethnic group. Yet even people with a Turkish or Russian background – two of the oldest and largest immigrant groups in Germany – have a low degree of organization. This lack of larger lobbying

groups and identities is even more true for the groups of recent refugees to Germany.

Taken together, the points raised above demonstrate the need to identify sociocultural reasons for discriminatory attitudes in public health information toward different population groups during the current pandemic and beyond. We argue that the most promising approach comes from combining the perspectives of disability studies, diversity studies, and medical ethics, as well as from collaborating with stakeholder groups and researchers who belong to these groups. At the Göttingen Medical Center Institute for Medical Ethics and History of Medicine we plan two exemplary case studies that will point to the societal barriers in providing inclusive and fair health care information and communication, and will provide a base for health care research in exceptional social situations such as a pandemic. Such an approach provides the analytical background to explore similarities and differences in societal perception in order to achieve barrier-free health care communication for the two groups mentioned here. In order to achieve this, we also plan to look at international best practice examples. We would be much interested to hear from our colleagues in international medical ethics on these issues.

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COURSE REPORT

“Genetic engineering – Crispr wonder weapon or devil's tool”

On 16th of November 2019 an advanced training course on the topic of gene editing took place at the University hospital in Zurich, Switzerland. The course was organised by the Alumni NDS-MiG association, which is based at the centre for health law and health management at the University of Bern (MiG). The association is a network of former participants of MiG advanced studies programs which are directed at health care management personal. The training course on gene editing was open to the public and attended by about forty people, most of them, though, were members of the NDS-MiG association.

The course included the opportunity to listen to important speakers of Bern Universities' collegium generale. Last autumn the collegium combined various interdisciplinary and public lectures on the topic of gene editing. The training course aimed to provide a comprehensive picture of genetic engineering by discussing it within the context of clinical practice, ethics and the law together with a previous scientific introduction to CRISPR/CAS. The overall question was asked within two extremes, namely whether gene editing was a “wonder weapon” or a “devil's tool”.

Each aspect was covered by a separate expert. Professor Heiner Niemann from the Medizinische Hochschule Hannover (MHH) gave an introduction to CRISPR focusing on xenotransplantation medicine. He was followed by Anita Rauch who is professor of Medical Genetics at the University of Zurich. Her presentation shed light on the main uses of CRISPR technology in relation to human patients. Then professor Markus Zimmerman from the University of Fribourg, who is also a member of the Swiss ethics committee (NEK) presented a critical outline of bioethics, current official guidelines and ethics; asking what questions a modern society should address. Professor Franziska Sprecher from Bern University and Co-Director of MiG summarised the legal questions gene editing gives rise to in Switzerland.

This advanced training event made immediately clear that gene editing goes with a wish to do good for patients and to ameliorate the world, but also with uncertainties, conflicts with the rights of future generations, technical risks and general safety issues. The invited experts succeeded to exchange knowledge about genetic engineering according to their speciality. The different perspectives were also made use of during the plenary discussion between the speakers and the public at the end of the course. It was moderated by Prof. Dr.

Christoph Zenger, Co-director of the centre of health law and health management (MiG).

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BOOK REVIEW

Baptiste Morizot. *Manières d'être vivant – Enquêtes sur la vie à travers nous*. Paris : Actes Sud, 2020.

Livre hautement intéressant, parfois déconcertant, qui veut montrer le besoin d'un décentrement, d'une approche nouvelle de nos rapports avec le Vivant. Je l'ai lu avec un sentiment de découverte de choses qui m'étaient cachées... Baptiste Morizot (1983) enseigne la philosophie à l'Université d'Aix-Marseille mais est aussi éthologue et coureur des bois et des montagnes ; notamment en accompagnant des équipes qui pistent les loups dans le Sud de la France - pistage vu comme la sensibilité aux signes laissés par d'autres formes de vie (noter aux pages 55 à 62 une discussion du hurlement du loup).

Prenant acte des enjeux écologiques systémiques, l'auteur aimerait remédier à la « crise de la sensibilité », à l'appauvrissement de ce que l'homme voit, sent et comprend de son environnement. Citant E.O. Wilson : « La vérité, c'est que nous n'avons jamais compris le monde ; nous croyons juste exercer un contrôle. » Un fil rouge du livre est la remise en cause engagée de la dualité Homme-Nature dans les anthropo-philosophies occidentales majoritaires (Descartes et les autres... mais Morizot rompt une lance en faveur de Spinoza). Doctrines qui nous dominent et mènent, c'est de plus en plus évident, dans des voies sans issue. C'est pourquoi le maître-mot est le « Vivant », nous *avec les autres*. Son plaidoyer, sa démonstration en fait : l'homme doit apprendre à se détacher de la pensée narcissique de supériorité spirituelle et technique qui le rend aveugle et sourd, pour aller vers une « approche inséparable du vivant ».

Parfois quelque lyrisme : « Nous avons tous un corps épais de temps ; au cours de millions d'années se sont sédimentées, chez des formes de vie très éloignées sur l'arbre du vivant, des dispositions et des tonalités qui se ressemblent. Des manières partagées d'être vivant. »

Morizot a dans la foulée des propos catégoriques sur la réorientation urgente des règles et moyens du libéralisme si souvent hors sol. « La conjoncture nous force à penser autrement pour faire de la place aux autres vivants et ne pas courir le risque, en contexte de crise systémique (climatique, migratoire, sanitaire, alimentaire) qu'ils disparaissent compétemment des priorités. Nous allons

tous [devoir] entrer dans une 'écologie de subsistance' ». Le dépôt légal du livre est daté de février 2020, l'auteur a-t-il pu tenir compte de la pandémie qui déboulait, qui rend d'autant plus aiguë la question ?

Pour une vie en commun satisfaisante pour toutes les parties (humains et animaux, sauvages comme domestiques), mettre en œuvre des mécanismes de « diplomatie interspécifique des interdépendances », que l'auteur discute en détail. Pour inventer les modalités d'une « cosmopolitesse » ! Cette diplomatie constitue à la fois une forme d'attention et un mode de résolution des conflits entre vivants, fondée sur la possibilité de communiquer ; allant ainsi contre l'idée que le seul rapport possible est de force. Travail d'intermédiaire, il ne s'agit pas de défendre un camp contre un autre. Le diplomate se met au service de la relation elle-même, de la manière dont les usages humains d'un territoire peuvent être combinés, tissés, avec des usages non-humains.

Il est certainement bon de se voir interpellé, déstabilisé, quand sont ainsi mises en cause des notions auxquelles nous sommes tellement habitués (piliers de notre décor... dualité Homme-Nature, libéralisme) que nous n'avons plus guère conscience qu'elles peuvent être discutées, voire réfutées dans leurs conséquences. Morizot fait cela en compagnon engagé.

Alain Damasio dans sa postface : « Comment construire une approche politique du souci porté aux relations [avec les autres vivants] ? Comment entrer dans un éthos de la rencontre, dans cette hospitalité envers le pas-comme-moi ? »

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BOOK REVIEW

Religion and Ethics in the Neonatal Intensive Care Unit

Ronald M Green and George A Little (Eds)

Publishers: Oxford University Press 2019

ISBN9780190636852

Around ten percent of new-borns require some medical intervention after birth. For the majority this is relatively brief, but a minority will need ongoing care in a neonatal intensive care unit. These may have a range of issues such as congenital abnormalities, sepsis, asphyxia or prematurity. The belief system of the family will influence how they approach decision making, how they weigh the value of life and the avoidance of suffering and influence their needs around bereavement. Neonatology is a relatively new specialty and issues such

as the appropriate response to extreme prematurity or predicted severe disability are not addressed specifically in any major religion but may be interpreted in a variety of ways.

This book has been written as a resource both for staff involved in neonatal care (doctors, nurses, allied health professional, psychologist and ethicists) but also for parents of neonatal patients and their faith leaders. It arose from a series of lectures given to the Annual Gravens Conference on the Environment of Care for High Risk Newborns. These lectures form the basis for this collection of essays. They cover a range of the major world religions including Judaism, Roman Catholicism, Evangelical, Denominational and African American Protestantism, Islam, Hinduism, Buddhism, Seventh-day Adventism and Navajo religions.

It sets out to address what the major religions teach about the moral status of preterm and sick newborn infants and how that may influence decision making. The authors span a range of disciplines such as religion, ethics, philosophy, theology, Buddhist studies, anthropology and neonatology. This brings both a breadth and depth to the subject matter covered in the book.

A number of themes occur across all of the chapters. The authors make it clear that no religion is monolithic. Many have sub traditions (such as Orthodox or Reform Judaism) while others may have a single authority (such as Catholicism) but have multiple interpretations on matters such as withdrawing life support. All religious traditions are evolving to address the issues that come with rapidly changing developments in neonatal care that could not have been envisaged at the time when teachings were originally laid out. When human life is believed to begin in a morally meaningful sense varies across traditions and is relevant to decisions around the care of infants born at the threshold of viability or at substantial risk of long-term impairment. Importantly it is clear that none of the religious traditions described are vitalist - that is none teaches that biological life must be maintained at all costs (although some believers may think that). Cross cutting across the whole book is the importance of "cultural humility" as opposed to "cultural competence". Understanding the importance of religious ritual and community to some families is a vital part of the family centred care which a core ethos of twenty first century neonatology.

This book can't, and doesn't, give the definitive view of each religion on every neonatal ethical dilemma. What it does offer is an intriguing insight into different religions and cultures and how they may influence families' approaches to decision making in NICU. For example, Bhattacharyya describes the plurality of traditions and beliefs for the Hindu with no distinction between religion, culture and life. One of the unifying beliefs is a belief in the unity of all living reality. A person with this world view is more likely to consider the needs of society rather than focus on individual rights. Muslim beliefs and practice are also diverse. Ayubi in her chapter on Theory, Praxis and

Authority develops two different models – Scriptural-Dependant and Ritual-dependant; while Tyebkhan writing as a Muslim neonatologist focuses on a specific denomination of Shia Islam – the Dawoodi Bohras. In the latter, significant decisions will be deferred to His Holiness the Da'i as the ultimate authority on earth. Ayubi discusses the implications for personhood and burial rites, the male dominance of decision making including the potential exclusion of mothers from end of life discussions, based on the Islamic literature and empirical studies.

While some of the chapters focus specifically on the religious teaching and beliefs, others highlight how religion and culture are entwined. In an enlightening chapter on the African American Protestant Perspective, Smith focuses on contribution of longstanding systemic racism to current health disparities in the USA and the role of African American Christianity to both bear witness to this and to fight for justice, taking its cues from the Biblical prophets. While the second half of his chapter is more focused on the black Christian tradition, the belief that all humanity is made in the image of God underpins the whole chapter – so that not only are all races equally important but every individual, no matter how preterm, disabled or deformed, has an equally high moral value. Schwarz, discussing the Navajo tribe, demonstrates the degree of culture clash between their world view and the ethics of health professionals. Their belief that babies are malleable, that all body parts (including breath) remain connected to that person for life means that they mistrust resuscitation practices for example. Not only may the baby live past their allotted time, but their body may have been contaminated for life by the non-Navajo breath. Similarly, blood transfusions should come from the same blood line.

Many authors bring some practical experience and highlight potentially problematic areas in clinical practice. Some of these are well known, such as blood transfusions or pork-based substances, others less so. For some religious communities the use of donor breast milk is highly problematic as it confers kinship. In the UK donor breast milk is anonymised, pasteurised, pooled and increasingly used routinely. The knowledge that this may be an issue for some families should inform consent processes. Lack of awareness of important rituals is equally problematic and possibly more common. While the importance of varying rituals around the time of death is usually appreciated, failing to consider birth related rituals, such as whispering of Islamic prayers into the ear of a new-born or the process of giving the baby a name may cause distress as families may not ask if it is not offered. It also becomes clear that the significance of some ceremonies (such as the emergency baptism of the dying baby of Protestant parents) lies in the recognition of the baby as part of the faith community rather than exclusively the protection of their soul.

Does this book meet its aim? Reading it as a practising neonatologist I would say that it largely does. It has

certainly earned its place on my bookshelf. It covers both the abstract theology and the day to day practice relevant to a multicultural community. The various authors convey the complexity of applying ancient texts to a new, rapidly changing specialty. The point is well made that not only will lay people be unaware of specific religious teaching, but many faith leaders will be equally unaware of how their religion regards very specialised situations such as occur in modern neonatology. This book would be an invaluable starting point for many. However it is an American book and thus some aspects are not applicable to the UK. Native Americans are uncommon in the UK, for example. The suggestion that it may be helpful and comforting for staff to discuss their faith with families and pray with them may be acceptable in the USA, in the more secular UK it would generally be regarded as inappropriate and potentially a disciplinary offence. Throughout the book various authors remind the reader that individual families may vary in their adherence or interpretation of their faith. It is not reasonable for staff to know all of the ideologies that their families believe or indeed assume that knowledge of religious teaching will predict an individual's beliefs. Bhattacharyya emphasises that developing cultural humility rather than cultural competency should be our aim. This is nicely summarised by Tyebkan, who ends his chapter by advocating neonatal staff to ask families two questions – “what is important for you” and “how can I help you”. Overall this is a well written, fascinating and useful book.

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BOOK REVIEW

“Parental Rights, Best Interests and Significant Harms: Medical Decision-Making on Behalf of Children Post Great Ormond Street Hospital v Yates”
 Goold, I., Herring, J. & Auckland, C. (eds.) (Oxford: Hart Publishing, 2019)

The administration of justice and the provision of medical care in the UK should be carried out without prejudice. However, both institutions are often subject to accusations of prejudice on the basis of class and race. In *Parental Rights, Best Interests and Significant Harms: Great Ormond Street Hospital v Gard* (‘the Book’) the exceptionalism of the *Gard* case is identified by the specific set of circumstances of the case as it pertained to an impasse where the Great Ormond Street Hospital (GOSH) should have allowed the *Gard* family to pursue an experimental medical treatment in the United States

as funded by *Gard* supporters. The question of why the case ‘drew substantial public attention’ is attributed to its imposition of the courts on parental authority. In the discussions around futility, vulnerability and conscience the chapters of the Book seek to discuss the decision making process of the legal system and medical providers; but it does not refer to other obvious factors as to what inspired significant public interest to inspire the decision making – Charlie *Gard* was white and his parents had the money to fight for experimental treatment.

The Book seeks a generality to provide relevant legal frameworks and cognitive schemas for healthcare providers to frame what constitutes the ‘best interest of the child’ and ‘significant harm’ in both the medical setting and in the courts. The interrogation and examination of existing frameworks provide nuanced and comprehensive understandings of where the *Gard* decision is positioned within statutory law and court precedents. But it does not sufficiently layer its analysis with why Charlie *Gard*’s life was given such a spirited defence within our legal institutions and why it was buoyed by public interest and support.

Marmot consistently argues that ‘the higher the social position, the higher the health’.[1] Charlie *Gard*’s parents were supplemented by vocal and generous benefactors that negated their own personal economic capital and they appeared sympathetic. Moreover, in July 2017, the Trump administration reached out to the *Gard* family to offer their support and Pope Francis preached that the *Gard* family should be able to “accompany and treat their child until the end”[2]. These are not irrelevant factors when contending with the questions of the value of human life. Political, social and economic capital form implicit biases that have been consistently proven to conclude in the unequal provision of medical care and legal outcomes.

In the *Gard* case, the outcome of the court or decisions by healthcare providers was not steered by the social and economic capital of the *Gard* parents. But the acknowledgement of the *Gard*’s unique position to advocate for their position and to object to GOSH’s decision was partially acknowledged in their proposed bill of *Charlie’s Law*, which would give parental authority more weight in the decision making of what constitutes ‘significant harm’. The proposed bill would provide parents access to Legal Aid if they needed legal support to advocate for their position to object to decision making by healthcare providers.

The social capital of whiteness that the *Gard* family used to generate public interest is difficult to quantify or definitively prove. However, in questions of medical decision making in terms of race, the COVID-19 landscape has proven that the NHS is unable to

adequately support BAME communities[3]. Additionally, as the prevalence of the impact of consanguinity in certain BAME communities leads to a higher rate of genetic deformity, it is of especial importance to form frameworks and cognitive schema in terms medical decision making in terms of the best interests of the child and the significant harms for further treatment. The citation of the case of *Re G* (a case where estranged parents from the ultra-orthodox Jewish Chareidi community disagreed about their children's education) in Rachel Taylor's chapter 'Parental Decisions and Court Jurisdiction' alerts us to the fact that race and religion may impact parental decision-making (in terms of education choices for children) but does not examine how that may impact medical decision-making or court processes in accommodating that parental decision making.

In contrast to the Gard case, the Abbasi family was not able to generate the same amount of public interest in the case of their daughter, Zainab in 2019. Zainab's parents, both NHS consultants, disagreed with a course of action that would result in palliative care being administered to their daughter[4]. The disagreement in the course of action resulted in Zainab's father being forcibly detained by police after he refused to move from his daughter's bedside to prevent further action by medical staff in administering their health plan for Zainab. Zainab's father said that "he believed if he had been white he would have been treated differently"[5]. The lack of similarity of the Gard family's reception by healthcare providers and the general public seems to immediately support Dr Abbasi's reflection of his treatment by legal enforcement and NHS staff.

The questions of class and race have not revealed themselves to be the central tenants of cases of the infringement of parental authority when it comes to the medical care of an infant patient, like Charlie Gard or Alfie Evans. But inhibiting factors of economic and social capital may inhibit such cases becoming subject to legal decision-making. But as greater public scrutiny is being invited on the NHS on its role in caring for the BAME community, in a post COVID-19 landscape, frameworks and cognitive schemas moored by ethical and legal understandings of the rights of all parties must also factor in the especial role of race and class in medical decision making and the provision of healthcare.

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DEADLINE NEXT NEWSLETTER

The deadline for the third edition of 2020:

November 15, 2020

If you wish to promote your event, or to inform your EACME-colleagues about the results of your work, descriptions of projects, book reviews etc. Any good ideas for the upcoming edition?

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