

Inclusion in times of disaster medicine¹

BODYYS statement on the current debate on triage which discriminates against disabled people

Merely 11 years after the entry into force of the Convention on the Rights of Persons with Disabilities (UN CRPD) in Germany, school closures caused by the Coronavirus pandemic is seemingly all it takes for its name to fade away. In these hectic times of medical crisis management, law and particularly human rights, are apparently not in the foreground of what matters. Yet, human rights offer especially in times of disaster an important roadmap to be included in decision-making to avoid an overall decline in rule of law performance. However, such an outcome will be the price to pay if the guidelines on the question of ‘whose life to save’ are left entirely to the discretion of Private Medical Associations. This includes the recommendations published by the German Interdisciplinary Association for Intensive and Emergency Medicine (DIVI) on ethical decisions on the allocation of resources in emergency and intensive care medicine in the context of the COVID-19 pandemic, which clearly violate the human rights in our Constitution, namely the respect for and protection of human dignity, as well as the prohibition of discrimination.

Background: DIVI recommendations

In its recommendations² for triage, the German Interdisciplinary Association for Intensive and Emergency Medicine (DIVI) advocates for treatment prioritization based on the principles of treatment needs and resource scarcity. Accordingly, the need for treatment should be determined in a multi-step process, either resulting in admission or discontinuation of intensive medical treatment. The decisive factor here should be the *prospect of success* of the treatment in terms of survival probability and life expectancy, which for each patient should be established on a case-by-case basis as opposed to the prospects of success of other intensive care patients.

In addition to the severity of the acute disease, *comorbidities*, that is other underlying diseases, and the degree of frailty should be included in the assessment. However, this is extremely problematic as the individual survival probability can actually not be predicted and may be misjudged if it is based on specific comorbidities. For example, survival probability also depends a lot on the quality of the intensive care. An assessment comprising life expectancy as a factor also worsens from the outset the prospect of treatment for many people with chronic illnesses.

The criterion of *frailty* relates to (age-related) reduced resilience and physical functionality and is measured on a scale (Clinical Frailty Scale–CFS). Medical lawyer Dr. Oliver Tolmein explains: ‘Clinical

¹ The DIVI statement (s. Fn 2) has been revised because of this and other counter-statements: <https://www.divi.de/aktuelle-meldungen-intensivmedizin> However, our main critique remains, because CFS is still applied.

² German Interdisciplinary Association for Intensive Care and Emergency Medicine (DIVI) (2020), decisions on the allocation of resources in emergency and intensive care medicine in the context of the COVID-19 pandemic. Clinical-ethical recommendations, online: https://dynamic.faz.net/download/2020//COVID-19_Ethik_Empfehlung_Endfassung_2020-03-25.pdf?_ga=2.118345609.1206587639.1585153435-1714784802.1582443029 .

Frailty Scale [is] an instrument that also plays a role in selection decisions in transplantation medicine and differentiates between 9 stages: from 1 (very fit) to 9 (dying). Stage 4 means 'vulnerable': no daily assistance from others required, but 'slowed down' or 'tired during the day', whereas stage 7 means 'very frail': due to a physical or mental impairment completely dependent on personal assistance, but stable and not at risk of dying during the next 6 months. In combination with the other factors, it is clear that, in addition to the elderly, in case of doubt people with physical and mental impairments can be classified in the group of patients not to be treated.³ Tolmein points out that the application of the CFS is not only used in dilemmas, as typically illustrated: Should the 79-year-old person with moderate severity of dementia be treated or rather the 44-year-old mother of three children? The algorithm of the 'recommendations' would however also as a result favour the 51-year-old family man without impairments as opposed to the 49-year-old father, who has multiple sclerosis requiring a high need of assistance, and the 17-year-old young woman with Down syndrome and a minor heart defect.

DIVI furthermore shares the opinion that in relation to the scarcity of resources due to the Corona-virus crisis, it is unjustifiable to apply the decision-making solely to the group of COVID-19 patients, but rather it should be applied to all intensive care patients.

Protection of human dignity instead of utilitarian considerations

Sacrificing the lives of some to save other lives is a violation of human dignity and the prohibition of discrimination in our constitution, both on a quantitative and qualitative level. The State must not sacrifice the lives of a few in favour of the lives of many others. This is also what the Federal Constitutional Court decided in the hypothetical case of a shot down hijacked plane which is directed into housing estate. Even the seemingly already lost passengers may not be sacrificed based upon utilitarian considerations.⁴ Age, disability, social status or any other characteristics must not be used to weigh up whose lives are to be saved. This is forbidden by the prohibition of discrimination in Article 3 of the Basic Law, which in its paragraph 3 stipulates that 'Nobody must be disadvantaged because of his or her disability.' The Federal Constitutional Court has on several occasions decided that the UN CRPD must be used for the interpretation of the Basic Law.⁵ The UN CRPD guarantees in its Article 10 the right to life of all persons with disabilities and stipulates in its Article 25 that persons with disabilities have a right to non-discriminatory health care and that State Parties have to 'prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.' Additionally, Article 11 of the UN CRPD reads: 'State Parties shall take (...) all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including (...) humanitarian emergencies and the occurrence of natural disasters.'

Protect persons with disabilities from discrimination

The DIVI-recommendations are characterized by their non-compliance of these human rights sources. The principle of equality is mentioned in great detail, even admitting that according to our legal system, neither calendar age nor social criteria should be the 'sole' criterion for such allocation

³ <https://www.tolmein.de/bioethik/details/artikel/triage-oder-inklusive-intensivmedizin-1373.html>

⁴ BVerfG, judgment of the First Senate of February 15, 2006 - 1 BvR 357/05 -, R n. 124.

⁵ BVerfG, decision of the Second Senate of March 23, 2011 - 2 BvR 882/09 -, marg. (52), online: http://www.bverfg.de/e/rs20110323_2bvr088209.html.

decisions.⁶ However, indirect discrimination against persons with disabilities and old people is unavoidable if based on factors such as frailty and comorbidity. The frailty assessment according to the CFS factors, such as the need for assistance and aids automatically leads to a lower rating, which means that the individuals concerned systematically present a lower chance of receiving emergency or intensive care treatment. Medical lawyer Dr. Oliver Tolmein summarizes: 'There is no need to phrase a recommendation that persons with disabilities should not receive treatment—the disadvantage here already results indirectly from the standardized criteria.' However, this is neither in compliance with our constitution nor with international human rights law, as both Article 3 (3) of the Basic Law and the UN CRPD (Article 5) prohibit indirect discrimination.⁷

The World Health Organization (WHO) has also already warned of an increase of discrimination against persons with disabilities in the fight against the COVID-19 pandemic: persons with disabilities are doubly life threatened—on the one hand they are part of a risk group highly vulnerable to the virus itself, and on the other hand, there is a risk that they will not be treated adequately once they are infected due to triage-like decisions.⁸

The use of the CFS for allocation decisions also implies an assessment of their lives which is not compatible with the respect and protection of human dignity according to Article 1 paragraph 1 of the Basic Law. 'Human life and human dignity enjoy regardless of the duration of the physical existence of the individual equal constitutional protection', says the Federal Constitutional Court unmistakably.⁹

Fortunately, the recommendations of the DIVI are not applicable law, but merely a 'decision support' for responsible actors. Their comments are expressly encouraged and updates will be announced.¹⁰

Ethics Council's position on triage weakens human rights

The German Ethics Council rightly pointed out that the State must not decide whose life should be considered as worth protecting and whose life should be sacrificed. 'Any direct or indirect distinction made by the State on the value or duration of life and every linked national requirement for unequal allocation of chances of survival and death risks in acute crisis situations are not permissible. Every human life enjoys the same protection. This not only prohibits differentiations based on gender or ethnic origin. A classification based on age, social status and its assumed "value" or a predicted lifespan must also be omitted by the State.'¹¹ However, he then goes on to unjustifiably put this decision in the hands of medical associations. According to the Ethics Council, 'the prohibition of state

⁶ DIVI (2020), p. 4.

⁷ BVerfG, decision of the Second Senate of June 18, 2008 - 2 BvL 6/07 -, marg. 49; United Nations Committee on the Rights of Persons with Disabilities (2018), General Comment No 6 on equality and non-discrimination, CRPD/C/GC/6, para. 18.

⁸ World Health Organization (2020), Disability considerations during the COVID-19 outbreak, WHO / 2019-nCoV / Disability/2020.1, online: https://www.who.int/health-topics/disability#tab=tab_1.

⁹ BVerfG, judgment of the First Senate of February 15, 2006 - 1 BvR 357/05 -, R n. 132.

¹⁰ DIVI (2020), p. 3.

¹¹ German Ethics Council (2020), solidarity and responsibility in the Corona crisis. Ad hoc recommendations, p. 3, online: <https://www.ethikrat.org/fileadmin/Publikationen/Ad-hoc-Empfehle/deutsch/ad-hoc-empfehlung-corona-rise.pdf>.

assessment does not entail that corresponding decisions cannot be accepted'¹², making specific reference to 'associations' which, 'in the context of the above reason can and should provide important guidance which content wise go beyond what would be permitted by the State.'¹³ Such a statement by the German Ethics Council promotes an attitude of 'necessity knows no law', which devalues any achievements in terms of human rights. However, in times of crisis, especially human rights provide support. They not only represent visions for a free and equal future, but they also prescribe the minimum standards of a dignity-based society offering security and protection for all people.

Demanding the state's duty to protect

If our legal system prohibits the triage-recommendations of the DIVI because they allow for utilitarian and discriminatory decisions, what is it then that we should do? To leave this question—and the consequent traumatic decisions—in the hands of hospital medical and caring staff alone is certainly the wrong way to go. Seemingly neutral algorithmic decision-making tools that will show the latest scientific evidence on artificial intelligence are not the solution either, because learning systems often take over discriminatory perceptions and more often even worse.¹⁴ In general, this is the assumption when it comes to the prioritization or allocation of limited or insufficient resources in emergency or intensive care medicine.

The State has a duty to protect persons with disabilities as compared to other risk groups in terms of discrimination and exclusion, especially when it comes to protecting the fundamental right to life (Art. 2 para. 1 Basic Law).¹⁵ The UN CRPD calls for a paradigm shift from a medical model to a human rights model of disability, which the State must ensure to also implement in disaster medicine.

Orient guidelines towards the constitution and human rights

Specifically, this means generating—for a limited time—guidelines based on human rights in a rule of law-based system. Disability must not be a criterion for withholding or discontinuing medical care, either directly or indirectly. If the State tacitly accepts discriminatory recommendations from professional associations, it makes itself complicit in the discrimination.¹⁶ The principle of subjection to the law, one of the essential principles of the rule of law, also requires that essential measures relevant to the fundamental rights of our society must be regulated by the legislature itself. It cannot be entrusted to private actors—even if they are medical associations—, sometimes not even the executive.¹⁷

The German Institute for Human Rights, in its Declaration on the Corona crisis, also points towards the important function of the legislature as a control and independent agency in emergency situa-

¹² German Ethics Council (2020), p. 4.

¹³ German Ethics Council (2020), p. 4.

¹⁴ Zuiderveen Borgesius, Frederik (2018), Discrimination, artificial intelligence, and algorithmic decision-making, ed. by Directorate General of Democracy © Council of Europe, online: <https://rm.coe.int/discrimination-artificial-intelligence-and-algorithmic-decision-making/1680925d73>.

¹⁵ BVerfG, decision of the First Senate of July 26, 2016 - 1 BvL 8/15 -, marg. 70, online: http://www.bverfg.de/e/ls20160726_1bv1000815.html.

¹⁶ Kees, Alexander (2011), Responsibility of States for Private Actors, Max Planck Encyclopaedia for International Law, para. 3, 9.

¹⁷ BVerfG, judgment of the First Senate of 9 February 2010 - 1 BvL 1, 3, 4/09 -, para. 136; BVerfG, judgment of the First Senate of 6 December 1972 - 1 BvR 230/70 and 95/71 -, para. 109.

tions. The content and limits of such guidelines would need to be based on the Constitution and international human rights.

In addition to the standards mentioned by the German Institute for Human Rights in connection with the Corona crisis,¹⁸ other important documents should be mentioned from a disability perspective in this context in addition to the UN CRPD as main legal source, which has so far received little attention in the discussion. This includes the thematic study by the High Commissioner for Human Rights on Article 11 UN CRPD published in 2015,¹⁹ the *Charter of Inclusion of Persons with Disabilities in Humanitarian Action*, signed by Germany in 2016,²⁰ as well as the Sendai Framework for Disaster Preparedness 2015–2030.²¹ They all emphasize the need for non-discriminatory and disability-sensitive disaster protection. They also refer to the State's duty to ensure that a triage situation does not occur, and if it does, that the principles already mentioned in the previous debate should be used: Every patient who can be treated with a prospect of success must be given equal opportunities. Both the priority principle (who was there first?) and the urgency principle (who requires treatment most?), as well as ultimately the random principle fulfil this requirement.²²

In these days, discussions about the opportunity for change in relation to the Corona crisis are rightly so ongoing and increasing. Let us make sure that change remains an opportunity for everyone and does not become a danger to some of us due to the current disregard of rule of law achievements as is the UN CRPD.

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¹⁸ German Institute for Human Rights (2020), Corona crisis statement: Human rights must guide political action, pp. 4-6.

¹⁹ Thematic study on the rights of persons with disabilities under article 11 of the Convention on the Rights of persons with Disabilities, on situations of risk and humanitarian emergencies, UN. Doc. A / HRC / 31/30, distributed November 30, 2015.

²⁰ See, <http://humanitariananddisabilitycharter.org/>.

²¹ United Nations, Sendai frame for Disaster Reduction 2015–2030 A / Res / 69/283, online: <https://www.un.org/depts/german/gv-69/band3/ar69283.pdf>.

²² Forum of disabled lawyers (FbJJ) (2020), Opinion on the recommendations of the professional associations in the event of triage, online: <https://abilitywatch.de/wp-content/uploads/2020/04/FbJJ-Stellungnahme-Triage-2020.pdf>; s. also Till Zimmermann (2020), Doctors in times of Corona: who dies first?, in: Legal Tribune Online from March 23rd, 2020, online: <https://www.lto.de/recht/hintergruende/h/corona-triage-tod-strafrecht-sterben-krankenhaus-entscheidung-wahl/>; s. also Tonio Walter (2020), Corona crisis: let the lot decide!, in TIME from 2 April 2020.

²³ Marité Decker