

COVID 19: Ethical dilemmas in human lives

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Abstract

On 7 May 2020, Columbia University Global Centers hosted an online international symposium on ethical dilemmas during the COVID-19 pandemic. This interdisciplinary engagement between philosophers and Covid medical professionals reports the challenges as well as the discrepancies between ethical guidelines and reality. This collection of presentations identifies four key ethical dilemmas regarding responsibility, fairness, dignity and honouring death. In looking into accountability and consistency in medical humanities, it examines whether the contextuality of coronavirus across countries and cultures affected the ethical decision-making processes. This work aims to provide a seminal resource for the development of a high-quality roadmap in medical ethics for future health crises.

KEYWORDS

epistemology, healthcare, humanity, medical ethics, philosophy of medicine, public health

1 | GENERAL INTRODUCTION

Dr Smadar Bustan, Philosopher

The novelty of the global outbreak of the highly contagious coronavirus disease brought the entire world together as it shared a collective experience, while at the same time, it pulled us apart with closed borders, home lockdowns, extreme social distancing, and isolation. This coronavirus threat presented a unique set of features: everyone had to be treated as potentially positive as it is possible to be infectious while being asymptomatic. Consequently, the disease often became a death sentence since there is no treatment or vaccine.

Moreover, our contemporary evidence-based medicine was challenged as the notion of knowledge became *in transitu*, knocking the solid bottom of the entire healthcare practice. Decisions need to be grounded in science but there was no science to rely upon. Information has been confirmed and refuted on a daily basis: face masks were publicly announced as protective measures but then their viability was debated; medical protocols at hospitals changed continually, confusing the frontline medical staff trying to save lives while feeding substance back to the experiential knowledge of medical care. Nations became indistinguishable by the worry and grief that joined hands: the long lists of hospitalized people shared on social media, the death



tolls portrayed by endless lines of military fleet transporting bodies of coronavirus fatalities for burial in northern Italy, the mass graves in Latin America or the extent of reported cremations of the COVID-19 victims in China, as well as the alarming cry of healthcare personnel worldwide.

The risk and prevention, required to limit the coronavirus spread and rapidly work out the most efficient containment measures, divided the tasks between the political, medical-scientific, public, and industrial sectors. Despite their exceptional collaboration, we seem to have turned back to population-oriented medicine after an accomplished era of personalized medicine, looking at the mass instead of the ill human being. In addition, when the whole world seemed to be coping as one, differences emerged in regard to national or even regional anti-COVID-19 management strategies, including sanitary and medical forms of intervention. Since the onset of the outbreak, while keeping people alive has certainly been the immediate and primary imperative, healthcare professionals have been overwhelmed by pressing ethical challenges, having to make hard decisions for which they were accountable and to provide reasons for their actions and omissions. Clearly, clinicians are trained for ethical decision-making, but in view of the pandemic chaos paired with the incredible shortage of medical resources, ethics committees or advisory groups had to help by providing specific guidelines such as those endorsed by the "COVID-19 ethical decision-making tool."¹

The reality was and still is represented as being constituted in the same fashion as that of decision-making in times of war where the urgency, scarcity of medical supply or critical care beds, rapid spreading of new cases, time-sensitive procedures, and fighting the unknown during a public health emergency continue to weigh efficiency (*Is it the most effective? What will be the end result?*) over the ethical (*Is it the right thing to do?*). The sensitive issue of medical rationing raised very important questions about "fairness" in the context of broader social injustice and was particularly noticeable during this global healthcare urgency. The dramatic phrasing regarding "the war against COVID-19" announced by politicians and health organization directors-general became integrated into the healthcare system. It forced challenges that no longer strictly applied to individual patient care (allocation of limited resources such as ventilators, the sharing of patients' confidential information with relatives or even the media, denying opportunities for families to say goodbye before a death) but also applied to the role of practitioners who found themselves in a newly created chain of command.

The essential service of medical ethics and its decision-making process, as I see it, consists in allowing for one part of the decision to lean upon another part of the decision in order to become unambiguous. In this way, each one of the several aspects in which the ethical decision may be considered, assures the fundamental values of the right and the good. Such deliberation is based on having a choice regarding which end to pursue. However, moral dilemmas put us in a situation of conflict where a difficult choice has to be made between different options where neither resolve the issue in

an ethically ideal acceptable fashion. Medical ethical dilemmas create even more conflict because they touch upon human lives. The COVID-19 pandemic obliged us all to handle many dilemmas, some of which we took upon ourselves as philosophers, ethicists, doctors and nurses to discuss during the online symposium *COVID-19: Ethical Dilemmas in Human Lives*, held on 7 May 2020, and hosted by the Paris Global Center of Columbia University and the Columbia Global Centers. We may not provide ready-made solutions here, especially as the epidemics storm still rages. This discussion testifies to the ongoing pandemic emergency and its difficult challenges while evaluating whether the ethical guidelines in the official healthcare recommendations were able to meet the lived reality. Looking at accountability and consistency in regard to the context of this global health crisis, it seemed equally important to examine, through an international exchange, whether the contextuality of COVID-19 across countries and cultures affected the ethical decision-making processes. The following collection of the symposium's presentations maintains the original discussion format, whereby each dilemma is addressed by a COVID clinician and then analysed by a philosopher or an ethicist, who, at times, is also a practicing physician. I organized the discussion around four notions depicting four key ethical dilemmas with leading questions, even though others clearly come up in the various discourses.

1.1 | The four ethical dilemmas

The following are the identified four key ethical dilemmas:

1. **Responsibility:** Can medical responsibility change in times of pandemic?
2. **Fairness:** In times of emergency, scarce healthcare resources, and risk of infection to the medical staff, how do we decide where we draw the line of whom we treat, who will live and who will die and how to ration treatment without denying care (triaging resources)?
3. **Dignity:** Does the need for increased awareness of public harm in a pandemic justify impinging on patients' rights to bodily and personal dignity and privacy?
4. **Honouring death:** Does public interest in social distancing outweigh the patient's right not to die alone and the family's right to be with their dying relative?

The challenging questions raised here are intended to reinforce our ethical values and speak of the well-being of the sick human being, the dignity of the dead person, and refer to a patient as a person to be cared for rather than a critical case or a contaminating agent. And while the coronavirus continues to widely spread across the globe, we hope that our discussion can serve as a resource for advanced care planning, helping medical providers and other specialists to consider the shared important aspects of medical ethics in times of great uncertainty.

For the symposium video, please view https://www.youtube.com/watch?v=07Nup9eMROA_

I would like to thank the Paris Global Center of Columbia University and their wonderful team for hosting the symposium in these exceptional times along with the Columbia Global Centers in Amman, Nairobi, and Istanbul. And last, I would like to thank all the healthcare and essential workers worldwide for their daily engagement to overcome the COVID-19 virus.

2 | FIRST ETHICAL MEDICAL DILEMMA: RESPONSIBILITY

Can medical responsibility change in times of pandemic?

2.1 | Responsibility: Mirco Nacoti, Clinician

Mirco Nacoti, MD (Italy), is an emergency, anaesthesia and intensive care physician at Bergamo Hospital, Italy. He has extensive field experience in humanitarian crises and community approach to vulnerable people.

Two months after the beginning of the crisis, I still have major problems sleeping.

I have dragged the corpse, from the bathroom to the bedroom, of a 50-year-old man who had died at home.

I have seen dozens of people piled up in emergency rooms with severe dyspnoea and frightened eyes.

I have spoken on the phone to a friend of mine and said to her: you must choose between your father and your mother.

I have run at night to my hospital, taken a drug for sedation and come back to look after an old man dying, as my hospital was too crowded.

I have obeyed an order to transfer to Germany by flight an intubated man and he has died on his way. I have never spoken to his parents.

I know many young anaesthetists in my hospital who have decided alone who were to live and who were to die.

I feel a persistent smell of people suffering on my skin.

The pale light of an old humanitarian actor, with some studies in bioethics, is now a fire. Forty years later, the Alma Ata definition² of primary health care seems vital to me.

I have done and watched a lot over these past 2 months. But my night-time question is: have I thought enough? That is why I am very grateful to have this occasion to think.

Bergamo is a rich and populous city of northern Italy (1 000 000 people) and one of the epicentres of the worldwide COVID 19. Despite the generosity of health workers, we are undergoing a severe humanitarian crisis that is stressing every aspect of daily life.

From outside it is very hard to understand, because houses are closed for lockdown and are not destroyed as they would be in an earthquake. Furthermore, in regard to the dilemma of moral responsibility, the World Health Organization (WHO) figures do not represent the reality. WHO is doing a great job, as usual, but the figures provided are a dilemma, as usually occurs during an outbreak. Today WHO shows about 3 500 000 confirmed cases with 240 000 deaths³

worldwide and in Bergamo 13 000 confirmed cases with about 2500 deaths.⁴ Unfortunately, the actual deaths reported by town halls are about 6000 to 7000 (nearly 1% of the population).⁵ Considering that a fatality rate of 20% is a non-sense, because the Chinese experience (even in Hubei province) reports a rate between 1% and 3%,⁶ the number of people contaminated in Bergamo is likely to be between 250 000 and 500 000 (which means 25%-50% of the population). More than 2000 people with mild-severe hypoxia, at the peak of the outbreak, stayed home because all the hospitals were overcrowded. These are the real figures. This is the picture of Bergamo's disaster.

For this reason, we wrote a paper, which appeared in the *New England Journal*.⁷ In regard to the dilemma of moral responsibility, when the global medical community is called on to face a pandemic of unprecedented scale, with little scientific evidence and "crazy numbers" describing the situation, honest and forthcoming advocacy is an ethical duty, and that paper was a wake-up call for those involved in system preparedness and strategic planning.

An outbreak is neither a simple disaster casualty incident like an earthquake nor a "simple" disease, but it is a social phenomenon. Historical and social elements are key factors for development (eg, intensive promiscuity between animals and humans) and spread (eg, health workers and ambulance rapidly become vector of the virus) of an epidemic.⁷

A first consequence of this translation into a social horizon concerns the theme of responsibility. And in regard to the dilemma of moral responsibility, how much does the social narrative about the infection numbers weigh, for example, on the decisions to be taken and on the concepts that guide them (eg, that of proportionality)?

How do inaccurate narratives, from an epidemiological point of view, affect the "judgement in situation," that takes place in triage or in prevention strategies in other countries? How many shocking images are needed if figures are not reliable?

Another aspect of the dilemma of moral responsibility concerns the care of decision-making process and the fragmentation of responsibility. Modern Western medicine has centralized the care of patients in the hospitals (and our region does represent this process), preventing the community from being the main actor in the sphere of public health and putting into practice an "expropriation of health," as Ivan Illich says in *Medical Nemesis*.⁸ Body has been progressively fragmented in small pieces by super-specialized doctors and responsibility has ended up being a question of legal responsibility, an economic matter, and not an ethical one. In this fragmentation, it has been acceptable for us to execute orders, even if epidemically dangerous or not ethical, because we were living an urgent situation, and during the fight against COVID 19 the mantra was "to do and not to think." It seems, as Hannah Arendt writes in her "Banality of evil," that "nobody was responsible, or rather, nobody felt they were; they just did their job."⁹ Would it have been useful to have a mechanism of control of decision makers in close contact with territories? Only the awareness that the weight of a decision is to be shared can prevent us from turning the triage into a moment of irresponsible superhomism.¹

A further aspect of the dilemma of moral responsibility is the ethics of the research in urgent situation. As Derek C. Angus wrote in

a JAMA view point,¹⁰ one stark example is the debate over prescribing available drugs, such as chloroquine, or testing these drugs in randomized clinical trials. At the heart of the problem is one of the oldest dilemmas in human organizations: the “exploitation-exploration” trade off. Exploitation refers to the “just do it” option. Exploration refers to the “must learn” option.

During his captivity in the 1940s, Archibald Cochrane treated many prisoners, often ill with tuberculosis, by observing how the disease benefited more from a good caloric intake than from drugs of uncertain or zero efficacy. The germs of Evidenced Based Medicine arose from those observations. Eighty years later, in regard to the dilemma of moral responsibility, how many helmets to deliver respiratory assistance have been placed without any enteral feeding in Bergamo? Chloroquine, antiviral, anti-IL6, anti-complement, steroids, and antibiotics have been distributed without a real methodological approach, without monitoring, with people arriving at the hospital worn out after days of dyspnoea. What data, what ethical research can be produced in such a mess, what if you publish on an important indexed medical journal but the “garbage in, garbage out” approach is still considered the right one¹¹? Furthermore, in regard to the dilemma of moral responsibility, what about signatures extorted for consensus from a dyspnoeic patient with no family member nearby? Such a touchy a matter would require competence and experience, and yet it was often managed by residents instead of specialists. Not everything is lawful in urgency and there is an ethics of research even in urgency.

Derek C. Angus suggests at the end of JAMA view point¹⁰ that an integrated approach of “learning while doing” is essential in a crisis. Nevertheless, in our current context, it is very important not to lose the capacity to think and probably we have to subtly shift from Angus' suggestion to a “thinking/learning while doing,” as Hannan Arendth writes.¹²

Goisis, a philosopher, co-author of the New England article, says that it is not true that nothing will be as it used to be before COVID-19. Millions of people in the world will be more vulnerable and isolated. But the economic, scientific, political, and social mechanisms leading to this pandemic humanitarian disaster are still there. “Doctors have to give back to the community the capacity to promote health,” could have said Ivan Illich today.

2.1.1 | Acknowledgements

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2.2 | Responsibility: Smadar Bustan, Philosopher

Smadar Bustan, PhD (France), is a philosopher, ethicist, and scientist at the University of Paris Diderot. In her research on human suffering and pain, she developed a tool for evaluating the disease-related suffering of patients following experimental and clinical studies in Luxembourg,

Germany and France. She co-founded at Harvard and heads the International Program on Suffering and Pain (www.suffering-pain.com).

The dilemma discussed here bears on responsibility, a Latin term from 1590 *respōns(us)* or response, which became philosophically prominent rather late in the 18th century. Our question is, does responsibility, and more specifically medical responsibility, change during a global health crisis? Is responsibility limited in the avalanche of an infectious transcontinental disease, obliging us to relieve clinicians from the burden of decision-making process carried out in individual cases?

A broader conceptualization of the nature of responsibility is necessary in order to deal with this dilemma, by first asking: *what does it mean to be responsible in times of pandemic?* Responsible behaviour during the coronavirus infection outbreak was very much present in every household and country around the globe. Yet the lack of adequate knowledge caused significant inconsistency leading to public panic and raised doubt about what it means to act in a responsible manner, both personally and collectively. The problem with a pandemic is that the personal and the social intermingle to the extent that the most casual individual acts, such as coughing, sneezing, going out of our homes, or walking around maskless, turns a person into a biological agent engaging into irresponsible behaviours that some would qualify as criminal or immoral. This COVID-19 Epidemic has been enhancing *mutual accountability* to such an extent that individual responsibility is transferred from an autonomous self to a self intrinsically bound to others. One can no longer exert free will to live carelessly and be prepared to risk contamination.

What we have learnt from this epidemic as a globalized society is that individual responsibility is no longer *exclusively centred* on what we are bound to undertake by duty, of a person being responsible for something or someone (a parent for their child, a doctor for their patient) since *simply by being, breathing, existing, we are accountable, all of us together and every one of us individually.*

Unfortunately, under such circumstances, our responsibility becomes as vulnerable as we are.

The fragility of a pandemic causing this involuntarily *responsibility by existence*, with its inevitable sharing of accountability, leads us back to our main ethical dilemma when asking what motivates us to make the right choice for a responsible act during a health crisis. For the overwhelmed practitioner inquiring how to fully know what the right act is, how to best choose in relation to the available resources and to whatever is in one's power, the resignation to do “the best we can” may provide protection from liability but not necessarily satisfaction or peace of mind. When the medical model of responsibility is guided by reasoned thought in regard to what we can do and the means that lead us to better ends, it is difficult not to notice the unrest when this intellect-based definition of being responsible entails a sense of feeling morally, medically or even humanly irresponsible. When reading Dr Nacoti's testimony, it becomes clear that even though a well-regarded thought led him and his colleagues to make decisions for saving lives, the strong remorse experienced following the death of their patients shows that a reason-based decision for acting

responsibly with a negative end result may leave clinicians with a feeling that they are partially at fault for the failure.

The severity of the pandemic has exposed many of the medical workers, as those in the frontline in north Italy where Dr Nacoti works, to face the toughest triage procedures in medical care with the prospect of having to ration equipment and care, sacrificing certain people for saving others and facing unthinkable choices regarding life and death. The lack of treatment led to the use of drugs on the basis of limited evidence concerning their effectiveness and therefore not without risk while trying to assure the highest rate of survival. In this respect, even when providing immunity against malpractice during the emergency of COVID-19 and hence excluding any legal responsibility, as Dr Fischkoff recounts about the State of New York in her discussion on fairness, the problem with ethical responsibility persists not only in regard to the possible damage caused by one's own act, but also to the consequences of this act on the people to whom they must answer. We find here the two aspects of the modern idea of responsibility, associating legal and moral responsibilities. The interdependence of these two aspects may explain why, despite excluding any legal sanctions and therefore legal responsibility in a time of unprecedented crisis (facing scarce resources and exceptional emotional burden on healthcare personnel), the ethical dilemma persists because medical decisions remain attached to our moral obligations. Treating clinicians whose actions are based on well-justified rational decisions may still carry blame, unable to wash away the guilt, because these fail to comply with their moral convictions.

The lived reality of the pandemic obliges us to go beyond the first form I named *responsibility by existence* to better examine the medically relevant form of *responsibility by deliberation*, introducing the idea of making a choice as a result of deliberation and of fully *knowing* what is the right thing to do. Two philosophers who represent this strand of thought with the traditional concept of responsibility as dependent on knowledge, striving to certainty and regulatively knowing everything or at least as much as possible, are Aristotle (4th century BC), in his account of Ethics, and John Stuart Mill almost two millennia later with his utilitarianism¹³ (19th century). In the third book of *Nicomachean Ethics*,¹⁴ Aristotle examines what is good for the human being – what we need to undertake, aim at, and act upon, in order to do good. In our case, medicine aims at health, and physicians aim at healing. In this respect, what Aristotle also taught us is that when we deliberate, we always have some end in view. If I deliberate about whether to put a mask, I consider this in light of a future end in view, which is to avoid catching or spreading the COVID-19 virus. If I deliberate about whether to respect the extreme social distancing of the quarantine and stay at home, I consider this in light of a future end in view which is to slow down and eventually stop the epidemic's spread.

Aristotle claims, however, that there are two things we cannot deliberate about: facts (which could only be examined) and end views, for the simple reason that we cannot change them. Hence our choice based on deliberation of doing good and acting responsibly are dependent on end purposes and on sticking to the facts, and basically on

knowledge. At the same time, if during the COVID-19 pandemic we apply this philosophical recipe with reason-based choices regarding medical responsibilities, we soon realize that clinicians are being severely undermined, which only intensifies our dilemma. In reality, we have witnessed misinformation emanating from situation reports and official communications, including from public health authorities, through inaccurate or misguided information. For example, It was said that smokers are less likely to be contaminated, ibuprofen or aspirin can worsen the coronavirus symptoms, or the virus is unstable at high temperatures and therefore will go away when the weather warms up. In the upheaval of the aggressively spreading epidemic, scientific facts continuously evolved so action based on facts had to adapt, inducing further confusion relative to our standard approach of evidence-based medicine that cancelled out knowing beforehand and making a contingency plan accordingly. Furthermore, at the outbreak of the pandemic, the end view of medicine and its therapeutic goals shifted from healing to prevention from dying, totally destabilizing the standard therapeutic goals.

Under a state of emergency and threatening rapid death, we could simply proclaim that without a solid foundation to rely upon for making choices, the entire undertaking of medical and social responsibility is bound to perplexities. Medical professionals must respond when facing flows of COVID patients with severe respiratory distress out of active commitment to vulnerable patients. De facto, they do respond. But do they need, in this unique scenario, to take responsibility for their medical response? In respecting their devotion and diligence, can we relieve clinicians from a part of the responsibility in the decision-making process as normally carried out in individual cases?

A comprehensive approach should be compatible with extant principles of responsibility under the given circumstances. A broad approach to analyse responsibility for pandemic diseases should consider both forms of responsibility, by existence and by deliberation. This would be better overall for society and healthcare, considering the disruption due to shifting facts and undermined medical ends, thus promoting more careful policies and actions.

At the same time, the outcome of the discussion so far has been to show us that a person or an act can be considered responsible so far as one is bound by it, or thinks it to be right. My first observation in examining “what is it to be responsible” in times of pandemic consists in introducing the idea of *responsibility by existence for all*, regrettably excluding the freedom to be able to do otherwise. And my second observation examining “what is it to act responsibly” consists in introducing the idea of *responsibility by deliberation*, of accountability for our actions and their consequences, and the praise and blame attributed to the moral agent. Deliberation is a reasoned thought about what we can change by our efforts and where we need to act differently in various occasions. And yet, in times of pandemic the foundation for well-reasoned and thoroughly discussed decisions, fostering a collegial consultation as standardly required, is damaged because neither the facts nor the end views are stable enough to serve as references for deliberately acting responsibly. Dr Nacoti raised this point when he spoke about referring to the general qualification of the COVID pandemic as a war with a chain of command



whereby clinicians were to simply obey, following the mantra of “do and do not think” and inexperienced doctors found themselves having to decide alone who will live and who will die. The resulting epistemological helplessness of the coronavirus pandemic sheds a new light on the idea of responsibility due to the conflict within the medical profession, naturally based on knowledge but confronted with a new situation of not knowing. This novel chaotic situation cancels Aristotle and Mill's rationalist view of acting by virtue and for the benefit of good on the ground of knowledge, as clinicians who have an occupation requiring them to be well informed in order to act responsibly lack in effect the necessary knowledge.

This outcome for the practice of medicine and our philosophical inquiry requires to rethink the notion of responsibility and moral obligation by moving philosophical fields, going from Aristotle's guiding but failing rationality to Levinas' field of ethical phenomenology. The reason is that none of the perspectives that have been actually presented here has paid full attention to a third form of responsibility, based on an entirely different philosophical pattern and that provides a way out of this dilemma regarding acceptable or unacceptable changes in medical responsibility in times of pandemic. This alternative view consists in arguing that responsibility is involuntary, not bound by rational choice, certainly not a deliberate one and is totally experiential. Becoming responsible for a sick person is imposed upon us by his needy, vulnerable presence when calling for help, often without words, in an appeal conveyed by the misery and helplessness of their facial expressions. This sense of ethical responsibility goes beyond that of a reflective commitment. And just like the first form of responsibility by existence, it separates one from oneself by giving precedence to the other person, while emphasizing here that this other person is weaker and more at risk. Levinas considers the experience of responsibility as what binds one person to another, as the foundation for humanity and ethics, which he demonstrates through the well-known theme of the meeting face-to-face, when encountering the face of the other person causes a phenomenological shock that makes one feel inevitably responsible for their fellow human being.¹⁵

I have to admit that in my writings on ethics and the sufferer and especially in my review of what I call the “French School of the Ethics of Suffering,”¹⁶ I always criticized this uncompromising level of responsibility and priority Levinas claims we can grant another person, even when we are ourselves sick, exhausted and emotionally strained.¹⁷ But when I caught the Corona virus at the beginning of the outburst here in France, the sense of responsibility and giving priority for the well-being of another took over me. My symptoms were mild, but sudden. I fell down on the floor without being able to get up again, feeling the chill and honestly the fright of the unknown progression of this aggressive virus that literally took control over my body within minutes. While lying on the floor, what bothered me most was the possible contamination of my children and particularly of my asthmatic elder son who was designated as part of the COVID-19 risk group. I was sick, not being able to give anything, let alone move my body, and yet, just as Levinas claims, the disinterested sense of responsibility towards another invaded me and my responsibility for not contaminating them became my absolute priority. It was not a

voluntary or deliberated sense of responsibility and it very much obsessed me when I was most helpless.

Obviously, one could contest this example by rightfully claiming that children are an extension of the parent (and therefore, in this case, of myself) and do not represent a “real Other” in the full Levinasian sense. And as I demonstrate in my book on Levinas' ethics, the unreflective encounter with the other person rather represents a situation that makes me surrender myself to them, often against my own will and without being able to expect anything in return.¹⁸ The other could be a stranger one has to commit oneself to despite wanting to walk away, a patient entering an already overbooked COVID unit whom an overburdened doctor would rather put to wait or a contaminated elderly person placed in the care of a scared nurse, wearing a plastic bag due to lack of proper protective equipment (reminding us of the institutional responsibility towards the caregivers and the safety protocols). The other person may even constitute a threat but since their urgent call for help precedes me and is imposed upon me immediately, I am obligated to be there for them, unable “to get out from under responsibility.”¹⁹ It is the lived experience and encounter between human beings that make us responsible, not knowledge or deliberation on the account of facts. Human responsibility is simply being there for the other, claims Levinas.²⁰ The activated sense of responsibility towards the survival of others places them first, prior to worrying about our own survival and prior to any conscientious processing. One is compelled to worry and care for the other says Levinas, since responsibility does not originate from within oneself, but is rather an *order* or command that one receives. It precedes us in the sense that it originates from a prior time and our ascendants (ancestors or past generations), as Ezekiel Mkhwanazi beautifully explains,²¹ it is pre-original.^{22,23}

In transposing this view to our discussed dilemma of medical responsibility, it soon becomes clear that what stems from this sense of duty, of a caregiver or a medical worker, is not a Greek agency or freedom to choose the good, but a fundamental archaic obligation of oneself towards another, and that it “commands me and ordains me to the other.”²⁴ In this perspective, this amounts to saying that our dilemma is cancelled since no judgement can be made about treatment or availability of the medical caregivers during a pandemic. Their mere presence beside a COVID patient's bed is a celebration of being there for the patient and of human responsibility at its best.

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3 | SECOND ETHICAL MEDICAL DILEMMA: FAIRNESS

In times of emergency, scarce healthcare resources, and risk of infection to the medical staff, how do we decide where we draw the line

of whom we treat, who will live and who will die and how to ration treatment without denying care (triaging resources)?

3.1 | Fairness: Katherine Fischkoff, Clinician

Katherine Fischkoff, MD, MPA (USA), is an Acute Care Surgeon and intensivist at Columbia University and is the Medical Director of the Surgical Step Down Unit. She is an active member of the Columbia Ethics Committee, the SCCM Ethics Committee and an ethics consultant.

Fairness has been a driving principle of the treatment of COVID patients throughout the pandemic response. However, given the overwhelming number of patients in New York City, the challenges to fairness evolved as the COVID crisis unfolded.

To begin with, on 18 March 2020, all elective and semi-elective surgeries and other procedures were cancelled in New York City to allow hospitals to free up resources in anticipation of the surge of patients.^{25,26} This presented the first questions of fairness. Patients who were scheduled for often time-sensitive treatments were postponed in order to be able to care for the thousands of COVID+ patients. This was, of course, not just a question of fairness, but also of patient safety, reallocation of resources and preservation of PPE. However, any time one group of patients is prioritized over another, we must ask ourselves whether the outcomes were proportional. In this case, the overwhelming answer is yes. Shutting down normal hospital operations was essential in being able to safely take care of the enormous crush of patients that presented. However, should there be another wave, the proportionate harm to those patients who would be postponed needs to be considered and alternative options proposed in order to avoid interrupting their care again.

The second question of fairness came when questions of triage arose. In the United States, there is a strong cultural and legal emphasis on patient and family autonomy. This American phenomenon persists in part because the health care system is so resource rich. As an example, New York State law in the form of the Family Health Care Decision Act²⁷ does not permit physicians to withhold or withdraw life-sustaining therapy over the objection of patients and their families. In this cultural and legal context, when the COVID surge began and there were serious concerns about scarcity of resources, the governor of New York decided that rather than approve a triage system to decide which patients would get a ventilator and which would not, he would work to provide ventilators for everyone and New York hospitals committed to rapidly expanding their intensive care unit (ICU) capacity.²⁸ My hospital typically has 117 ICU beds but over the course of 2 weeks, we expanded to nearly 300 ICU beds and pop up tents provided extra inpatient beds. This was done without a compensatory increase in staffing. But because of this, no patient was turned away.

In 2008 after the H1N1 flu outbreak, many states put together a resource allocation plan that could be used in the case of crisis when resources were overwhelmed. The New York State Ventilator Allocation Guidelines²⁹ were built on the ethical principle of fairness that all patients would be given equal access to ventilators regardless of

socioeconomic factors. It begins with a set of immediate exclusion criteria that are applied to a patient when he or she is determined to need a ventilator, such as unwitnessed or recurrent cardiac arrest, severe traumatic brain injury or irreversible hypotension refractory to fluids and pressors. If a patient meets any of those criteria, he or she is not given a ventilator but is offered either best medical management or palliative care. If a patient needs a ventilator but does not meet any of the immediate exclusion criteria, he or she goes on to evaluation by a "Triage Committee" which follows a very specific pre-determined algorithm to decide whether a patient would be given access to a ventilator.

The goal of the Allocation Guidelines is to determine a patient's access to a ventilator based on prediction of likelihood of survival and not based on value judgements. In fact, to uphold the fairness of the process and to ensure there would not be any decisions based on social or economic factors, the triage committee is a third party whose representatives are not directly involved in the care of the patient and does not receive any demographic information.

As noted above, the Allocation Guidelines were not activated during the COVID crisis. With an incredible show of collaboration, creativity and immense hard work, hospitals in New York City were able to care for all patients who had COVID. The question must now be asked, is it ever fair to activate a triage process and deny access to critical care resources if there is the option to stretch resources further? The Institute of Medicine describes the spectrum of hospital expansion in response to a public health emergency.³⁰ Conventional capacity is the normal operating capacity of a hospital. Contingency capacity is defined as operating significantly above a hospital's usual capacity but is a state in which normal standards of care can be delivered. Crisis capacity is the final stage in which hospital resources are stretched so thin that normal standards of care cannot be provided. It is often recommended that triage systems be activated before a hospital enters crisis capacity as a mechanism to help avoid providing crisis standards of care.

New York made a decision to enter crisis capacity rather than activate a triage system. This necessarily meant that hospitals were providing crisis standards of care to *all* patients rather than normal standards of care to *fewer* patients. Nursing and physician ratios were tripled, non-ICU trained physicians were caring for ICU patients and all manner of hospital spaces were repurposed to create rooms for ICU level patients. One particular example was the provision of dialysis. So many critically ill patients required dialysis that hospitals quickly ran out of machines and supplies.³¹ This meant that in some cases, in a manner not consistent with typical standards of care, patients received fewer hours of dialysis than normal or had peritoneal dialysis as a manner of stretching the supply of dialysis to meet the demand.

As an acknowledgement of crisis standards of care and in order to support clinicians' ability to continue to care for so many patients, the governor of New York passed the Emergency Disaster Treatment Protection Act.³² The Act's stated purpose is to broadly protect health care facilities and professionals from liability for the treatment of patients during the COVID-19 pandemic. The Act shields health care professionals from civil and criminal liability in connection with



services provided to any patient as a result of and during the COVID-19 crisis, so long as decisions are made in good faith. For decisions that are alleged to be unlawful, the Act also provides immunity if they result “from a resource or staffing shortage.” Such legal protections were imperative to allow healthcare workers to continue to practice in the crisis environment but also are a recognition that the provision of crisis standards of care may contribute to adverse events.

While there are many ongoing conversations about whether New York should have activated triage systems, I have never been prouder of my city and my colleagues for their response to the COVID crisis. Taking care of nearly 120 000 New York City patients required perseverance, courage, resourcefulness and a willingness to accept personal risk. It will be months before we have outcomes data on the COVID patients and even longer before we will fully understand the consequences of our decision to treat all New Yorkers. But until then, we can stand tall in the knowledge that while our healthcare system was under unprecedented stress, we performed heroically and fairly.

3.2 | Fairness: Triage in the name of quality of life? Mylène Botbol-Baum, Philosopher

Mylène Botbol-Baum, PhD (BELGIUM), is full professor in the faculty of Medicine and Public Health IRSS in the Biomedical Ethics Unit (HELES), member of the Ethics Committee (INSERM France) and Professor in the Philosophy Department, at UCLouvain, Belgium.

Katherine Fishkoff has been addressing the issue of fairness from a regulatory perspective and the responsibility of the mayor of New York who has decided to protect medical doctors from trials when they take a reasonable decision in a context of emergency. These decisions raise dilemmas linked to conflict of interests and interpretations around the word fairness and even about what constitutes a fairness dilemma.

My first question, as a European benefiting from a providence state, is at what condition can we have fairness in an unfair system, that is, a non-egalitarian context? What are our basic assumptions about moral reasoning when we address dilemmas in situation of uncertainty?

We must take seriously the health system capacity of anticipation that refers to public health at large since the issue of fairness is essentially a biopolitical issue, which has global consequences during a pandemic.

We know that the pandemic reduction was not a priority for the US government, and many other opulent countries did not prepare adequately for it, so that the enormous responsibility to confront it befell on the medical providers. This imposed on them an uneven focus on present day patients, rather than the actual and prospectively sick. If we speak of fairness, we state that reducing the pandemic risk is a global public good inscribed in a complex temporality.

- Who gets healthcare resources?
- Can it be based on meritocracy, age, or function?

- Can we apply the same principles to all COVID-19 and non-COVID-19 patients?
- How to prioritize access to healthcare?

According to American bioethicists, referring to utilitarian principles, maximizing benefits is the most important principle, followed by the principle of care vs stewardship of resources.

Prioritization should aim at both saving the most lives and allowing empowerment of individuals post-treatment (definition of *Dalys*: to ensure future years of life with minimum handicap).

But what about the subjective perception of quality of life?

What kind of dilemmas are we confronted with, if we take the subjective dimension of quality of life seriously and not only Qualys?

Dr Fishkoff underlines the dilemma of providing medical assistance below our standard of care to all patients, vs normal standards to fewer patients.

Is this a dilemma between equality vs quality of care?

How does the notion of fairness lead us to respond and resolve, or not, the dilemma? It seems to me that there is no dilemma here when the basic principle is care. We should indeed maximize care. For instance, New York has a good public health system and has prolonged the obligation of social distancing. It should therefore not suffer too much of scarcity of medical resources leading to dilemma.

If we want to solve this dilemma in terms of rational arguments, we can address:

- Moral intuition
- Symmetry
- Incommensurability of the previous point

Dr Fishkoff tells us that the extreme shortage of dialysis machines conflicts with caring for all, which does not support a systematic account of triage. The difficulty is that the modern notion of dilemma confronts us with an impossible choice, even though to exclude the possibility of dilemma moral rules are precisely established to prescribe the choice of one action and exclude the other. This dilemma problem can thus be divided into two correlated parts:

1. The epistemological choice where it is logically difficult to determine what is my duty, when facing scarcity of ventilators for instance (either/or).
2. When both actions are necessary, but I can only do one of them, I encounter my finitude and my own vulnerability to act as an agent of choice.

So that any agent of care, or doctor here, is confronted with two sorts of conflict of obligation narratives:

1. One obligation is stronger than the other (so the conflict is not a real one).
2. The two obligations are equivalent, and I am facing an unsolvable dilemma because, in terms of fairness, there is no hierarchy between the two choices.

But during a pandemic, which is a natural and societal threat, we are facing the fact that rules can be consistent only if the context of disruptions of my narrative representations, my narrative world, can remain a consistent world as well.

In this disruptive moment, one realizes that rules are only useful if there are circumstances in a possible world of coherence, which is precisely what we lose in a situation of emergency, where all priorities seem to be reversed.

Choosing is the first duty in a situation when there is a clear hierarchy between the duty of care and the efficiency rule. In a state of uncertainty and urgency, the agent chooses first and foremost according to what I called her moral intuition. Facing a dilemma, she will use reason or moral rules to prioritize her decisions. These two states might be in tension with the efficiency logic of a public health ethics, where the collectivity is supposed to come before the individual interest of the singular patient, as if the collectivity was not constituted by individuals. Therefore, in a situation of uncertainty, I would prefer to advise the bottom up approach that combines moral intuition and rationality around the notion of quality of life. The reason is that it associates fairness as a form of loyalty to a subjective vision of quality of life or standard of living.

Indeed, the concept of fairness was developed within a framework in which tastes or values, although varying among individuals, remain constant.

We understand at this stage that the notion of fairness is hard to use in the contingencies of a pandemic. Perhaps this is because, during a pandemic, socially accepted values can be toppled upside down. This could explain that, in New York, egalitarian care became the priority over the rationing of care, which is the accepted cultural model in a highly competitive society based on meritocracy.

The climate of uncertainty and the sudden lockdown allowed for the surrealist scenario that all former economic priorities have been put aside from a quasi-species survival instinct.

So, what could have been a dilemma in normal settings? Economics vs Health becomes evidence in terms of moral intuition in times of pandemics.

This fact is very reassuring about the human pragmatic capacity to develop solidarity, above the logic of distributive justice and the utility level associated with it.

In Amartya Sen's terms, "Quality of life should come before Qualys in order to maintain capabilities and functioning."³³ Life expectancy after the pandemic in opulent societies, in terms of future opportunities and capabilities, are precisely not invariant. They are related to the well-being and capabilities of surviving individuals. *Dalys* is a measure of the burden of diseases, which combines time lived with a disability and the time lost due to premature mortality, estimated with respect to a standard age-dependent life expectancy. So, the notion of time lost because of the burden of a disease is very important to correct the abstract notion of fairness.

This leads me to have a critical gaze on a notion of fairness based on mere rationality.

3.2.1 | Rationality and consistency

In terms of rationality, the main rule of public health ethics is that whatever rule is chosen must be applied consistently. Reasonable life expectancy does not consider the dimension of narrative or care ethics. Is it fair, can it be justified? For instance, young vs old, and the equal value of life. One of the main issues of triage is the discrimination based on age. When do we begin to count the value of life? Is a foetus more important than a teenager? The idea of withdrawing treatment in a situation of scarce resources, in order to provide a respirator to a younger person for instance, may reach consensus in times of war, but here the metaphor of war is certainly not appropriate. This pandemic emphasizes mostly a bad governing of resources and not a lack of resources in the long term. The lack of anticipation cannot justify withdrawing treatment. It would be unfair.

In a utilitarian model, scarce resources go first to efficient patients. What do we lose in such a simplistic model? Should we provide care only to those who have instrumental value? This should be a societal choice, which goes far beyond medical ethics and raises true biopolitical dilemmas of distributive justice. Do we want to survive in a society of care, or in a mere society of efficiency? We have known this situation in Africa for access to drugs during the HIV/AIDS epidemic. Drugs were so scarce that medical doctors had access priority, but then nothing was left for the patients. The efficiency model can thus lead to absurd decisions, if no good decisions can be made to resolve the dilemma.

3.2.2 | Rationing policies and the limit of their rationality

Is a pandemic the appropriate moment to erase the plurality of judgments and stop weighing each particular case in the name of urgency? The risk of non-transparent rules of experts is to lose the confidence of the public. Real time decisions are certainly harder than applying efficiency rules. We should make room to moral intuition in entering the framework of decision that leads to adapt the rules in context. Should ethicists then help apply guidelines or assist with rationalizing decisions? I doubt it. It would mean to transfer the responsibility from the patient or his/her family to other efficiency bodies. I would suggest avoiding these real and false dilemmas to prevent the scarcity of medical resources by collaborating in solidarity with those who are still handling the matters, the medical doctors themselves.

Paradoxically, this pandemic has isolated half of humanity. It reminds us first that we are all mortals, and that is what makes us equals. Secondly, solidarity is the main ethical principle to escape from false dilemmas. What is a false dilemma? It questions rational evidence in the face of moral intuition. It is interesting to note that no regulation of triage rules has been adopted internationally, which reinforces the decision-making dimension associated with the survival and the preservation of people's abilities to survive. It could simply mean that it is a matter of isolating patients at risk of dying or losing



their motor or cognitive abilities, if they are not treated, as an arbitrary priority of these rules, or at least their relativity and adaptability.

These reflections force us to redefine the fairness models introduced in this rationalizing, and to rethink a model of public health founded not only on data driven medicine, but on deep and responsible democracy.

Can we really talk about scarcity, in our societies of abundance, or is it more linked to ineffective management of priorities for the social good, or to inadequate assets management?

The question will be *why*, and many speakers in the public debate have stressed the unpreparedness of most states. It will also be necessary to ask in what healthcare model this unpreparedness has been possible, to clearly determine the responsibilities shared among the different actors. We talk in peace time about the prioritization of care, but some rulers preferred to talk about war, a term used to justify all ethical transgressions. The wording of scarcity conditions is not acceptable. It is necessary to give common reasons to all caregivers as well as to the patients and their loved ones.

The procedural decision grids exist, but they do not free the medical doctors from the difficult freedom of personal responsibility in the heat of the moment. These tools are necessarily incomplete and therefore do not exist, because a clinician will always have to use his ethical imagination to practice a coherent care, adapted to any context and to a diversity of needs in terms of gender, race, or class, having fairness as its main horizon.

Indeed, if these decision-making grids are tools that have some effectiveness in the emergency, we must not overlook the after-effect of these decisions on the doctors and nurses in the aftermath of pandemics.

Prioritization is a societal choice that makes us all co-responsible. The main issue remains prevention, which can avoid both lockdown and tracking, and foster collective intelligence instead of infantilization. Fairness is thus more than equality because it is sensible to plural forms of vulnerability, while always aiming at the recovery of capabilities for each person. Fairness is a plastic notion that implies the articulation of care and justice.

4 | THIRD ETHICAL MEDICAL DILEMMA: DIGNITY

Does the need for increased awareness of public harm in a pandemic justify impinging on patients' rights to bodily and personal dignity and privacy?

4.1 | Dignity: Laure Madé, Nurse

Laure Madé (FRANCE) is a practicing COVID-19 Nurse at Hospital Bichat, Paris, and Epidemiologist. Trained as a nurse in France, she completed the MSc in Epidemiology at the London School of Hygiene and Tropical Medicine. She has been working on emerging infectious diseases at Institut Pasteur.

I worked as a nurse in a COVID-19 ward in a French hospital in Paris during the COVID-19 outbreak. The Bichat hospital is a referral hospital for the treatment of emerging infectious diseases and a leading player for the management of epidemic and biological hazards. During this unprecedented sanitary crisis, I witnessed numerous situations where health professionals faced ethical dilemmas in human lives. After fighting tirelessly against COVID-19 in France and overseas, I am still wondering whether we can effectively control this outbreak while treating both patients and the deceased with sensitivity, dignity, and respect.

In early April 2020, we were overwhelmed with the media coverage on COVID-19. Many patients in an artificial coma were exposed to French TV news as an attempt to raise awareness of the threat of the unseen virus. In France, patients have to give consent to appear on TV, but this is not mandatory if they are unconscious as long as their face is covered. According to French law, the consent of the people filmed is not required when the image is illustrating a topical subject. I did not experience this specific situation as I was not working in the ICU, but I know some colleagues who felt uncomfortable dealing with this specific situation and found it particularly inappropriate.

We experienced other dilemmas during the outbreak that went beyond the media issue. What called my attention was how the patients were extremely terrified by being infected with COVID-19. It was indeed a new disease, very contagious with no proven treatment available. Every single health worker was entirely covered up with protective personal equipment: mask, gloves, gown, cap, glasses, and so on. All doctors looked similar and patients could not differentiate the many different nurses. This was a very stressful environment for them. On top of that, we could not enter the COVID-19 rooms as often as we wanted because we had to restrict our visits to limit the risk of contamination. Relatives and close friends were denied access for the same reason. In many rooms, COVID-19 related news was displayed repeatedly on TV screens leaving these patients with feelings of loneliness, isolation, and fear. They were fortunately allowed to keep their phones with them and could, therefore, maintain a much-needed virtual contact with their loved ones. Despite these challenges, we tried our best to reassure them, and we made sure to provide emotional support every time we interacted with them.

The fact that our country was unevenly affected meant that a lot of human and material resources were allocated to the most affected areas. We did not experience a lack of staff, as hundreds of health workers came to help from different cities, including medical and nursing students. We were lucky to have at least one nurse for every four patients in the non-ICU. However, we had severe issues accessing personal protective equipment, especially appropriate masks.³⁴ This was a major challenge because we really wanted to give the best care possible to our patients, but we also needed to feel safe and protected ourselves. We had an incredibly high number of sick colleagues, and we even had to resuscitate one of them who was hospitalized in our ward. The feeling of fear was shared by everyone, patients, and health workers alike.

Finally, COVID-19 protocols in place at the time also impacted the way we handled the deceased bodies. Whenever we had a death

in our ward, which was unfortunately frequent during the outbreak, we had to put the body entirely naked in the mortuary bag.³⁵ This situation was distressful as we felt that we could not honour the deceased properly. We were not allowed to dress them up and the family was not allowed to view them. The rationale behind this recommendation was to limit the risk of contamination after death even though no evidence of transmission of SARS-CoV-2 through the handling of the body of a deceased person has been documented. The French High Council for Public Health amended its recommendations end of March³⁶ when the risk of infectious transmission from bodies was proven to be lower than for living patients. They allowed the viewing of the body for mourners immediately and the presentation of the body to the family. However, these less stringent guidelines did not reach our hospital.

During this pandemic, health professionals faced ethical dilemma situations more frequently due to various factors such as time required for the healthcare system to adjust to the crisis (hiring extra staff, set up of space/beds for patients, procurement of appropriate protective equipment, etc.), intensive workload among others, and potentially impacting the standard of care. But despite this stressful period, our intent was always to keep humanity in the care provided. Finding the right balance between the need to control the infection and the respect of the patient's and families' rights is a difficult exercise, but the dignity of the patients and the deceased should be respected and must remain a priority, even in such chaotic time.

4.2 | Dignity: Rita Charon, Ethicist, Narrative Medicine

Rita Charon, MD, PhD (USA), is Chair of Medical Humanities and Ethics at Columbia University. A general internist and literary scholar, she is the founder of the discipline of narrative medicine. With an MD from Harvard, PhD in English from Columbia, she conducts research on the impact of humanities in medicine and is the author or co-author of four books on narrative medicine.

I want to thank the Columbia Global Centers in Paris, Amman, Nairobi, and Istanbul for sponsoring this symposium and insisting that the pandemic is an international pandemic. The more we can remember that we are not isolated and not solving our own parochial problems, the more effective and just will be the outcomes of our actions.

Ms. Madé has just given us major testimony not only about the privacy and dignity of the patient's body but also about the privacy and dignity of the other bodies in the room. I am very impressed with what she just did. Here is why. I am a general internist and a literary scholar. I study narratology – how stories are told and understood and received and what happens in the world by virtue of the accounts we give to one another. A group of humanities scholars and clinicians at Columbia University developed the field of narrative medicine in the early 2000s.³⁷ We knew that the humanities, especially literary studies and creative arts, could make powerful contributions to health care practices and concepts not just through the content of great novels like *Magic Mountain* and *Frankenstein* but by harnessing literary and

aesthetic concepts of representation, close reading, inter-subjectivity, temporality, and embodiment for use in the clinic. Our work over the years has demonstrated that narrative skills can improve clinical care in many ways, including expanding clinicians' knowledge of individual patients, strengthening teamwork, and reducing burnout.^{38,39,40} It is through the many-focaled lenses of narrative medicine that I have approached this essay's effort to reflect on issues of privacy and dignity in the time of COVID.

The impressive part of what Ms. Madé just did, speaking from a narrative medicine perspective, was to nest the clinical dilemma of the nurses and physicians within the more encompassing clinical dilemma of the patient, allowing her listeners or readers to consider the embodied landscape of care as a whole. She started with the privacy of patients' bodies before and after death, outlining France's policies of privacy and confidentiality accorded to patients and their surrogates. Then she seamlessly drew in the opposite face of privacy of the clinicians' bodies – not that they are unduly exposed but that they are unduly concealed in their personal protective equipment to the point that patients and families cannot distinguish among their encapsulated bodies. Through that deft narrative turn, Ms. Madé encourages us to consider the patient and the clinician as a unit – one sick, perhaps dying, the other risking sickness, perhaps death in the effort to care for the patient. The fear for the clinicians' own lives and the fear for their colleagues' lives cannot be separated from their fear for the lives of their patients, levelling the typical hierarchy by the mournful, terrifying facts of this crisis.

We know that physicians in particular hold strict taboos regarding their physicality within their professional actions. Usually, the body of the physician does not enter the picture of medical practice. Touching of patients is strictly governed (although such rules do not prevent the occurrence of sexual assault on patients by their doctors). Grueling medical training drills the importance – and heroic implications – for doctors to do without sleep and food and ordinary physical self-care. It is not a surprise to learn that doctors are found to have greater levels of anxiety about death than non-doctors but find powerful ways to repress such fears.⁴¹ So Ms. Madé's testimony gives us an important and rarely articulated aspect of not just the ethical dilemmas of this crisis but a profound paradox of health care in which some who work very closely with dying persons are perhaps ill-prepared to deal with their own and others' mortality.

Doctors' fear of death notwithstanding, Ms. Madé's testimony emphasizes the collective nature of our ethical responses to this plague. Moral philosopher Charles Taylor situates his understanding of personhood within the collective: "One is a self only among other selves. A self can never be described without reference to those who surround it... A self exists only within what I call 'webs of inter-location'."⁴² Framed by Taylor's recognition of our webs of meaning-making, I will emphasize in the rest of this essay those relational, cultural sources of the moral compass that governs the actions of any one of us. Like literature itself with its invisible and necessary congress between writer and narrator, narrator and reader, and reader and character, our inner lives and our consequential outward actions are influenced by and opened up by our inter-subjective contact with



the other. With our patients and clinical colleagues, we are fellow mortals, siblings under the planetary and even cosmic horizons that locate us in time, space, and being.

Questions about the privacy of patients' bodies are old, old questions. Read the *Journal of the Plague Year* of Defoe and Camus's Dr Rieux in *La Peste* again if you have not done so recently to see how these questions of privacy, ownership, and custody of patients' bodies dead and alive have been with us in all the plagues of the 16th and 17th centuries and beyond.⁴³⁴⁴ Remember too, and this has been mentioned in earlier testimonies in this symposium, that the hospital is a strange insoluble mix of public and private. Illness itself is a subjective experience, a meaningful experience that happens within the context of an individual life as it is at the same time a public situation where some informal or professional group has to do the best they can to care for and protect others. The public functions, however, risk precluding attention to the individual's subjectivity; as phenomenologist Hans-Georg Gadamer asked, "Can science be connected once again with our own lived experience, or must the experience of one's own individuality be lost irrevocably in the context of modern data banks and new technology?"⁴⁵

It was in the 18th and 19th centuries that the hospital became, in the works of Foucault anyway, a place not where persons were cared for but the place where physicians and scientists were able to study and objectify their human bodies.⁴⁶ Physician and philosopher Mark Sullivan observes that "[i]n the new secular hospital [of the 18th and 19th centuries] organized by disease categories, the patient's body became the object of scientific study and the focus of clinical medical efforts. Patients with chronic illness that could not be treated successfully within the hospital or clinic were generally sent away."⁴⁷ The reductive efforts to study the heart, the lungs, the kidneys so as to learn and not necessarily to be with those who were suffering altered the nature of medicine indelibly towards a time when hospitals needed public policies to protect patients from medicine's intrusions and instrumental uses of the bodies of others.

But it was not until 1914 when Benjamin Cardozo wrote his decision in *Schloendorff v. Society of New York Hospital* that we had a firm legal platform, at least in the US, to say the patient's body belongs to the patient. The plaintiff had given permission for an examination under anaesthesia, but while the patient was anaesthetised, the surgeon removed a tumour from the abdomen. Cardozo's judgement was very clear. If a surgeon were to operate on a patient without their consent, the surgeon would be liable to charges of criminal assault.

With that rather sordid history as a background to this questions of privacy and dignity of patient's bodies in our hospitals, let me turn to the traditions and schools of thought that were not available to Defoe or Rieux in their prior very similar plagues and that now might help to guide us towards respectful and ethical care of patients in this time of COVID. Professor Bustan referred to the work of phenomenologist Emmanuel Levinas in the context of the subjectivities and inter-subjectivities of clinical care. The

phenomenological traditions within continental philosophy are poised to articulate the peculiar dilemmas of illness and embodiment – how individuals find themselves within the world through the sensations and affordances of the physical body and how one embodied person is recognized and called into being by the fact of another embodied person.⁴⁸ The body is the avenue through which the self lives in the world. Without our bodies, we are not in the world. Through our perception, sensation, and motility, we are able to not just address but to come into contact and to confront the real, whatever the real might mean. Without the body, we would be left only with our own imaginary representations of what we might intimate is out there.

Situations of health care, especially the hospital during a time of plague, poignantly enact the dramas of the body and the self that Heidegger, Husserl, Merleau-Ponty, and their followers so deeply investigated. Such contemporary phenomenologists as Drew Leder and Havi Carel continue the work of phenomenology by examining questions of social justice – imprisonment and maltreatment of animals – and the plight of individual patients whose serious and sudden illnesses derail their ongoing lives.⁴⁹⁵⁰

When I discuss the body of the patient, I do not invoke the Cartesian assertion that one can think of one's body as if disengaged from or outside of it but, in Gadamer's words, of "the absolute inseparability of the living body and life itself" (⁴⁵; p. 71). And so it is that I particularly appreciate Ms. Madé's comments on dignity, coming from the perspective of the nurse, that the body of the clinician as well as the body of the patient is involved in these clinical questions. More than medicine, nursing has been influenced by and has been the source of care ethics and feminist ethics formulations that bear on our question. The ethics of care, as proposed by Carol Gilligan in the 1980s and continued by Nel Noddings and Joan Tronto, among many others since then, focus on the relationship aspects of care.⁵¹⁵²⁵³ From the perspectives of care ethics, clinicians must be present themselves in order for care to be ethically and clinically effective – present not just in their cognitive and diagnostic capacities but in their moral, values-based, and even physical incarnations in the orbit of the patient. Such an ethics is a highly "costly" personal one, shifting the notions of duty from disengagement to engagement. I believe this ethical perspective clarifies some aspects of the dilemma we are faced with here. As one follows the literature in the ethics of care and feminist bioethics, one sees expansion beyond its initial focus on the perspectives of women in health care towards non-gendered formulations of relational moral visions, spreading from health care and education to inter-sectional, global, political, and economic issues.⁵⁴

At their cores, the feminist approaches in bioethics and care ethics formulations seat the personal commitment of the caregiver – family, teacher, health care provider, legislative representative, policy maker – to address both the impersonal and personal dimensions of the situation and its ethical calculus. The "address" is one-to-one, with the one who is cared for – in whatever situation – and the one giving the care as partners in the outcome. In our COVID setting, the patient's body is in the clinician's hands. The patient's body has been entrusted to this clinician who is present in her own body, however

protected or unprotected from the physical and existential contact she may be.

I conclude this essay by thinking back to our opening case, that of the cameras in the ICU taking images from the bed of a dying patient to broadcast those images into the public media. However protected such photojournalism might be by France's equivalent of the US freedom of speech laws and however allowed such photographing may be by the consent of surrogates, it seems to me like a greedy gesture on the part of the media to take and display what they think will be most shocking and the most potentially "viral" of images. I wish the photographers were more skilled than that. I wish they could capture perhaps less violent and intrusive but perhaps more telling images. We all probably remember the Holocaust photographs of the pile of children's shoes that most spoke to the horror of that genocide. So my closing request is a request for nuance instead of flamboyance, depth instead of shock. What we have to endure in the pandemic requires our capacity to see in great, great detail and delicacy all that unfolds, to not be catapulted to facile and false conclusions but to take the measure of the complexity of the time and the need for our utmost discretion in learning and teaching its lessons.

5 | FOURTH ETHICAL MEDICAL DILEMMA: HONOURING DEATH

Does public interest in social distancing outweigh the patient's right not to die alone and the family's right to be with their dying relative?

5.1 | Honouring death: Meinhard Kritzinger, Clinician

Meinhard Kritzinger, MD ICU-Anaesthesia (Italy), is a specialist in anaesthesia and intensive care with diploma in tropical medicine and public health. He has trained in Austria, South Africa, Italy, America, and in several war zones working for MSF-Italy.

I am a consultant in Intensive Care Medicine and Anaesthesia working and living in South Tyrol, the northern most Italian province bordering Austria. We serve a population of 500 000 people with one large and four smaller hospitals, all with ICU facilities. The experiences I will recount are based partly on my own experiences and experiences of fellow doctors working in the wards.

The 1990s was the last time that a special Italian law for infectious diseases was applied for the then new "AIDS epidemic." When HIV patients were admitted to hospital, they had to stay in a newly constructed unit, which had negative pressure isolation rooms and closed doors. The rooms had glass panels facing balconies and the visitors could see their relatives through the glass window.⁵⁵

Since there were no real therapeutic options at this time, those patients did not have any contact with relatives or the outside world. Their families could only see them from the balconies through a closed and locked glass window. As knowledge about this disease

improved, this inhumane practice was abandoned. Little did we know that 30 years later, this practice was to be reintroduced.

On 31 January 2020, a state of emergency was declared and a COVID task force, introduced by the Italian Ministry of Health, was created to handle the health emergency crisis and to govern all clinical decisions.⁵⁶ End of February 2020 saw the beginning of a widespread lockdown following the disastrous spreading of the disease in the Province of Bergamo, situated 2 hours south of our hospital. There were dramatic pictures from the overflowing emergency departments and ICUs. The first cases in South Tyrol were diagnosed at the beginning of March with the peak around middle of April.⁵⁷

In the subsequent weeks, the number of ICU beds was increased from 25 to 60. This was achieved by converting operation theatres to ICUs, and normal wards were converted to COVID only wards. Triage units were created and doctors from other departments such as dermatology, urology or ophthalmology found themselves in charge of newly admitted patients with almost daily differing case definitions and treatment protocols. Diagnostic pathways and responsibilities changed throughout the emergency, and doctors who never had seen a patient die under their care, had to face dying patients every day.

By the beginning of April, at the peak of the epidemic, sick patients were flown out to Germany and Austria. The daily death count reached 10 patients a day with 234 patients admitted to different hospitals in the region.⁵⁸

When caring for terminal patients in ICU we would normally invite family members to spend the last hours with their loved ones. Despite strict visitor regulations of only one close family member per patient and only close family, in such situations, makeshift rooms were created with privacy screens, so that family could accompany their loved one.

In the normal wards, family would be given ample space and possibility to talk to nurses and doctors while staying with the dying patient. Once the death had occurred, the corpse would be brought to the hospital chapel, where the deceased would be dressed and rested for 24 hours. This allows friends and family spend some time in prayer with the deceased since it is not customary to display the deceased in an open cask at the funeral in our region. The next day, the mortician would remove the body for the funeral, which takes place after a couple of days. Cremation is the exception since people like to see a coffin at the funeral and not an urn.

During the COVID epidemic, a "no visitor" policy was strictly enforced by the task force for COVID but also non-COVID patients. Doctors shifts were adjusted on daily basis as the workload dramatically increased. Changing diagnostic pathways and triage options left patients on the ward with a different doctor being responsible for them almost daily. Dermatologists and ophthalmologists, who had never cared for dying patients, let alone discuss terminal care faced difficult situations, as they were never trained in this area. Daily increasing patient numbers, uncertainty and fear to get infected decreased the time, that staff interacted with family and patients to the absolute minimum. Personal protection equipment with mask,



gown and a triple layer of gloves did contribute to reduce any personal contact.

The majority of the COVID patients were elderly and they had to stay in an isolation room, deprived of human contact during their final hours. In contrast to people dying of other diseases, patients with COVID sometimes were lucid until the very end. They were well aware that they were suffering from a disease where no cure was known and they were about to die from it. Nursing staff even at the deathbed was reduced to a minimum for fear of contagion.

Not only did the patient have to die alone, sadly even family members were also left on their own. They could not leave their house as lockdown prohibited all movements so they could not even meet to mourn.

In addition, frequently an elderly spouse was left alone at home confused and startled by having to stay in quarantine, with their partner taken in an ambulance with people dressed in gowns and masks, only to have him or her back as ashes in an urn a week later.

Once the death had occurred, the corpses were undressed and soaked with disinfectant and zipped into a plastic body bag. There was no way any relative could see the deceased, nor was it possible to dress the body with clothing sent from the family.

Once the ashes were returned to the household, funerals were limited to 10 people attending and lasted for a couple of minutes only.

To alleviate their patients' final hours, the nursing staff would sometimes stick printouts of photos of the family onto the surrounding walls, so that the patient could picture the presence of their loved ones in the room. In one case, a little dog was smuggled into the isolation unit for a quick farewell as this was the patient's last wish. In other cases, the relatives could see their loved ones through a glass window standing on the balcony of the isolation unit. Even though the regulations were uniform in the whole province, they were only strictly adhered to in the main hospital. In the smaller hospitals, one family member with protective clothing could sit with their dying relative.

The provincial ethical committee was aware of this problem and on the 1st of April, they wrote an urgent letter (attached in Appendix) to the task force regarding the increasing loneliness of the patients, the lack of patient's involvement in therapeutic decisions and access to terminal care (Irmgard Spiess RN, Alessandro Felici MD, e-mail communication, April 2020). Unfortunately, this letter was never published nor did the task force respond to this letter.

It was as if regarding the dilemma of honouring death, the epidemic had abolished patient's rights.

5.2 | Honouring death: Jeremy R. Simon, Philosopher and Clinician

Jeremy Rosenbaum Simon, MD, PhD (USA), is an emergency physician, medical ethicist and philosopher of medicine on the faculty of Columbia University. He is a member of several local and national ethics

committees and chair of the International Philosophy of Medicine Roundtable, the leading organization of philosophers of medicine.

The question at hand is Honouring Death: Does the public's interest in social distancing outweigh the patient's right not to die alone and the family's right to be with their dying relative? The issues raised by the situation Dr Kritzingler describes in this regard need to be ethically analysed on two levels. The first is the question of the nature of the rights under consideration, and the second is the question of the nature of rights in general at this time of public health crisis.

The dilemma as posed presupposes two different but related rights. That of the patient not to die alone, bereft of their family, and that of the family members not to be separated from their dying loved one. Of course it would be difficult to honour one of these rights without honouring the other, but with two rights in play, there are more arguments to be made in favour of respecting them.

One might think that right of the dying person is the more powerful right here. The dying are often given special consideration due to their status, even those being executed (last meal, cigarette, blindfold). The right to have comfort in dying, which ordinarily is not problematic, would seem to be something patients are entitled to. And certainly on some level they are. Being alone in a stressful time is frightening, and patients have a right not to be subject to undue fear. But if we focus on the right to visitors particularly of the *dying*, and not all patients, this right may seem to be somewhat reduced, especially in the current situation. First, patients can only be considered dying for a brief part of their hospitalization, when it becomes clear that they cannot be kept alive much longer, or when life support is being removed. Thus, any harm that may be caused by violating this right is mitigated by the relatively short time during which the right is being violated and the patients are exposed to unnecessary stress. Second, and this is relevant particularly to COVID, a large percentage of the patients who die are intubated and sedated at that point. Even to the extent that patients in general may have a right not to die alone, it is not clear that this right extends to unconscious patients. This is not to say that it does not. It may be an intrinsic matter of human dignity not to be abandoned at the time of death. But, even given that, hospitalized patients are not abandoned; they are not even without those who care for them. They are just without those with whom they have long-term bonds of affection. Note that the second point is of limited applicability, since many patients also die without being intubated. In those cases, the other arguments presented here will have to suffice.

What then of the family? They are conscious, and the harm done to them could potentially reverberate for years to come. And familial rights are certainly recognized in medical ethics, at least when it comes to surrogate decision-making. Perhaps it is their right that is stronger. But, whether or not it is stronger, it cannot be absolute. For, there is a very simple case where a hospital may, and must, keep out such a visitor – at the patient's request. Likewise, if the family member has behaved badly, even to the staff, during prior visits. This is of course not what is happening here. However, it does show that the family's right to visit is defeasible.

These, then, are the rights in question. What I have shown thus far is not that they do not exist here, just that they may not be as solid

as they at first appear. The next question is, how should we approach rights during the time of a pandemic. Traditionally, ethical analyses can be broken into two types, consequentialist, or outcomes-based, and deontological, or rules-based. A consequentialist, or utilitarian, decides whether an action is right based on the outcome that results – did the action create more good in the world than the alternative? A rules-based ethicist sees whether an action follows certain ethical rules – thou shall and thou shalt not – without looking to see what the impact is of following the rules in a given case. But that dichotomy is a bit misplaced here. Even a deontologist, a rules-based ethicist, may have rules that take into account outside impacts. So to have a specifically rules-based argument that visits to the dying is a right at this time, one would have to have a rule that implied that not only was it a right, but that it was a more or less absolute, first-tier right that no amount of bad consequences could override. I have trouble seeing this in general, and certainly in light of the arguments made earlier.

That was a bit quick I am afraid. The main point was just to argue that we need to analyse the ethics of our dilemma, as to whether the public's interest in social distancing outweighs the patient's right not to die alone and the family's right to be with their dying relative, based on the real world consequences of taking one side or the other, and not based on abstract, timeless rules. Therefore, we are left considering the consequences of allowing or not allowing visits to dying patients during the COVID pandemic.

Ultimately, answering this question requires objective data, or at least assumptions about such data, about the risk to visitors of acquiring COVID (and then also perhaps spreading it to others) and the risk of their already having COVID and spreading it within the hospital. This is information that I do not have. It also depends on the organization of the ICUs and the potential for disruption visitors could create. I know that at our hospital at Columbia, operating rooms have been converted to ICUs, so that in addition to the MICU, or medical ICU, and SICU, or surgical intensive care unit, etc., we also now have a new beast called the ORICU, for operating room intensive care unit. These do not necessarily have the same space and barriers that normal intensive care units have, and may have less room for extra people in them.

How could one use this information to make decisions here? Certainly, if wearing a simple mask is enough to prevent getting or spreading infection, then the danger to the visitor, the other patients, and to society at large is not a real issue, and is not a reason to forbid visitors. Of course, we do not know this to be the case, and so this danger must be considered. Given the degree of disruption to everything else that our assessment of the risk from COVID is causing, it is not unreasonable (though not necessary) to take a conservative approach here too. Note that the risk to the visitor is only part of the issue here, and so we cannot simply leave it up to them to take on the risk or not.

But even if the risk of virus transmission is small, the disruption to the intensive care units, and especially the makeshift ones, could be real. And I think that there is an argument to be made that if some intensive care units cannot have visitors, none should.

At the very least having different policies for different units would lead to arbitrary distinctions between patients, and at the worst it could lead to placing patients in preferred intensive care units for non-medical VIP (“Very Important Person”) reasons, which is certainly unjust.

Thus, I think that while keeping visitors away from dying patients is certainly a bad thing, it is not an absolute wrong, and may indeed be justified at times, perhaps even now. We broadly restrict rights during public health emergencies, and the right to visits is not stronger than many of these, and is perhaps weaker than some of the even more fundamental rights, such as engaging in religious worship and commerce, that life under COVID has, of necessity, interfered with. Nonetheless, if it is possible to have a safe, nuanced policy, with small numbers of visitors to those patients who would benefit from it, this is certainly desirable.

Any philosophical analysis of difficult human issues is in danger of losing the human, even when the analysis is rooted in the real world. Without pulling back from the somewhat difficult conclusions I have presented, I would like to pair them with a quotation from Rodrigo Marquez. Marquez is the son of the novelist Gabriel Garcia Marquez, author of *Love in the Time of Cholera*, and the quotations comes from a column he wrote as a “letter” to his late father, describing the pandemic to him. He says: “It's not just death that frightens us, but the circumstances. A final exit without goodbyes, attended by strangers dressed as extraterrestrials, machines beeping heartlessly, surrounded by others in similar situations, but far from our people.”⁵⁹

CONFLICT OF INTEREST

All authors declare no potential conflict of interest.

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ENDNOTE

¹ I refer here to “superhomism,” as interpreted by Gramsci, depicting the tendency to conceive of the individual affirmation as an “expansion of the personality without moral constraints.”⁶⁰ Originally, superhomism is the concept of the Superman by Gabriele D'Annunzio and which has been historically read through the lens of an autobiographical and intellectual superhomism, whereby female characters fade into the background, often considered minor figures, either passive-ethereal helpers or more active but negative antagonists, always bound to the male protagonists.⁶¹

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