

The Endocrine Ethics Association

Pandemic Ethics Considerations for the field of Endocrinology*

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Introduction: Caring for your Endocrine Patients During the Coronavirus Disease 2019 (COVID-19) Pandemic

Major pandemics and other natural disasters affect endocrine patient populations in very unique ways. These patients typically have many co-morbidities such as obesity and related complications, and diabetes and related complications. Interruptions in insulin or other hormone replacement therapies may in turn make quarantine more difficult. In addition, thyroid cancer patients whose surgical procedures may have been delayed can be at risk for disease progression. Patients with autoimmune disease may be undergoing therapies that may place them more at risk of infection. Pediatric patients may be especially affected when caregiving and school closings place additional burdens on families.

Endocrine practitioners may also experience moral distress and moral injury over difficult triage decisions, including delaying patient procedures and visits; limitations of telemedicine, shortages of personal protective equipment (PPE) and medical supplies, as well as coping with re-deployment.

Covid-19 and Diabetes Mellitus

Diabetes mellitus (DM) has long been acknowledged to increase risk of infections and result in poorer outcomes. DM has been shown to increase mortality risk in previous coronavirus illnesses (Severe Acute Respiratory Syndrome (SARS) and Middle East Respiratory Syndrome Coronavirus (MERS-CoV)) as well as influenza. While still being assessed, initial data on COVID-19 outcomes, signals that that DM may be a risk factor for mortality. Because of this, patients with DM are considered “high risk” during this pandemic. While data on risks associated with glycemic control is not available, endocrinologists encourage optimal individualized control and compliance, as this has been shown to improve outcomes with other infections. Therefore, it is key that these patients have access to their medications and providers to achieve good glycemic control. The American Diabetes Association has provided the following information to diabetic patients regarding their risks: (<https://www.diabetes.org/coronavirus-covid-19/how-coronavirus-impacts-people-with-diabetes>). Unfortunately, mortality statistics with Covid-19 show serious and grim health disparities in outcome, and patients with type 2 diabetes and complications are being put at greater risk with current guidelines surrounding re-opening in the context of insufficient testing and screening.

This resource addresses pandemic ethics frameworks, and introduces specific endocrine ethics frameworks for the field of endocrinology during a pandemic crisis..

Background: The Origins of Pandemic Ethics

The field of Pandemic Ethics emerged as a legitimate subspecialty of bioethics in the wake of SARS in 2003, and amidst anticipation of a bird flu pandemic, which the SARS episode exposed as a potentially more problematic pandemic without more focused planning.

Origins of the Core Literature: SARS and H1N1

In 2005, a novel Canadian Report emerged from the SARS experience entitled *Stand on Guard for Thee: Ethical Considerations in Preparedness Planning for Pandemic*

Influenza (University of Toronto, 2005). This report outlined the first ethical framework to guide planning efforts in the health sector, and led to a major research effort at the University of Toronto to establish an internationally focused Program of Research on Ethics in a Pandemic. This program published a White Paper Series in 2009, titled *Ethics and Pandemic Influenza* (CanPREP, 2009). In 2008, in anticipation of concerns over H1N1, the World Health Organization (WHO) published its own White Paper series titled *Addressing Ethical Issues in Pandemic Influenza Planning* (WHO, 2008).

Literature post-Hurricane Katrina

In the United States, Hurricane Katrina in 2005 led to several disaster planning protocols* that invoked the Toronto and WHO core pandemic ethics frameworks. Several papers citing that core literature emerged in this period in anticipation of either novel influenza or other natural disasters (Christian et al., 2006; Hick et al., 2007; IOM, 2009; Tabery & Mackett, 2008). In 2013, Sherry Fink published *Five Days at Memorial* (Fink, 2013), which revealed how quickly unprepared hospitals can reach conditions that wartime triage decisions, overwhelming healthcare providers in the absence of clear guidelines and questionable hospital systems leadership.

Literature post-Ebola

In 2014, the Ebola epidemic in Sierra Leone, Liberia, and other sites in Africa led to conclusions that the world was unprepared for a looming Ebola pandemic. A World Health Organization (WHO) working group formed in the wake of the Ebola crisis that led to a 2016 pandemic ethics publication entitled *Guidance for Managing Ethical Issues in Infectious Disease Outbreaks* (WHO, 2016). The 2016 document covered a broad set of ethical concerns related to infectious disease outbreaks, citing much of the early literature that codified pandemic ethics frameworks. In its Introduction, the document notes [emphasis ours]:

This guidance grew out of concern at the World Health Organization (WHO) about ethical issues raised by the Ebola outbreak in West Africa in 2014–2016. The WHO Global Health Ethics Unit’s response to Ebola began in August 2014, immediately after it was declared a “public health emergency of international concern” pursuant to the *International Health Regulations (2005)*. That declaration led to the formation of an Ethics Panel, and later an Ethics Working Group, which was charged with developing ethics guidance on issues and concerns as they arose in the course of the epidemic. It became increasingly apparent that the ethical issues raised by Ebola mirrored concerns that had arisen in other global infectious disease outbreaks, including severe acute respiratory syndrome (SARS), pandemic influenza, and multidrug-resistant tuberculosis. However, while WHO has issued ethical guidance on some of these outbreaks, prior guidance has only focused on the specific pathogen in isolation. **The purpose of this document is to look beyond issues specific to particular epidemic pathogens and instead focus on the cross-cutting ethical issues that apply to infectious disease outbreaks generally.** In addition to setting forth general principles, it examines how these principles can be adapted to different epidemiological and social circumstances.... While many of the ethical issues that arise in infectious disease outbreaks are the same as those that arise in other areas of public health, **the context of an outbreak has particular complexities. Decisions during an outbreak need to be made on an urgent basis, often in the context of scientific uncertainty, social and institutional disruption, and an overall climate of fear and distrust.** Invariably, the countries most affected by outbreaks have limited resources, underdeveloped legal and regulatory structures, and health systems that lack the resilience to deal with crisis situations.

The Ebola epidemic revealed that weak governance or infrastructure in many regions seriously impeded epidemic preparedness as the Africa-centered Ebola epidemic

quickly became difficult to contain and manage (Sun, 2014), and healthcare workers became infected and died. Additionally, priority for treatment was given to American healthcare providers over local healthcare providers, raising serious questions about the transparency of resource allocation decisions (Achenbach and Dennis, 2014). The 2016 WHO guidelines discuss macro-international and global health initiatives, such as proactive global surveillance, the role of non-governmental organizations (NGOs) and medical charities, and how pandemic prevention is wholly interdependent on the governance and foreign policy of wealthier countries (WHO, 2016).

The American Ebola Experience

When the first American Ebola patient, Thomas Duncan, presented to an emergency room at a Dallas, Texas hospital in 2014, it was clear that the hospital was completely unprepared (Berman & Brown, 2014; Spigner, 2014). The patient was first discharged with active symptoms, exposed several in the general public, and then later returned for care. Absent clear protocols, two nurses became infected caring for Duncan. Aside from contracting a life-threatening virus, the infected nurses suffered moral distress and moral injury due to poor planning and health disparities (National Nurses United, 2014).

In the wake of the American Ebola case, and the clear vulnerabilities revealed in the U.S. healthcare systems, several states began to formulate their own pandemic ethics planning documents which are listed in Appendix 1.

Pandemic ethics literature 2016-Present

A new literature search was conducted in March 2020. Data saturation was reached when it became apparent that the core University of Toronto (2005; CanPREP, 2009) and WHO documents (2009) continue to be the seminal texts that inform the substantive literature worldwide with respect to pandemic ethics. In the wake of the 2019-20 novel coronavirus COVID-19 pandemic, the core pandemic ethics frameworks established by the University of Toronto and the WHO remain the operative ethics frameworks and are treated similarly as the core bioethics principles developed by Beauchamp and Childress (1978), which are routinely cited in medical ethics content. Several bioethicists are now using the early Toronto and WHO frameworks to craft their own pandemic ethics hospital policies. Additionally, scholars who study the history of infectious diseases and government responses, such as the 1918 influenza pandemic (Barry, 2005) or the missteps in the early days of human immunodeficiency virus (HIV) (IOM, 1995), also inform this current pandemic event. Recently, Italy has published its triage ethics tool for rationing treatment for COVID-19 patients, which was translated March 13, 2020, by the UCLA Center for Ethics (see Appendix 1), while news reports from healthcare providers dealing with COVID-19 in countries that peaked earlier are sharing data freely in this fast-moving crisis.

Summary of the Core Pandemic Ethics Issues

The core pandemic ethical issues we discuss in this resource comprise: (a) duty to care of health professionals; (b) priority setting (resource allocation) of limited health resources; (c) restrictive measures (e.g., quarantine); and (d) global governance. The need for an ethical framework to guide local pandemic planning has been reinforced in multiple

disciplines engaged in pandemic planning. Ultimately, the public health goals identified by Pandemic Ethics researchers comprise:

- building and maintaining public trust
- protection of vulnerable populations
- establishing the obligations of health care workers in a pandemic
- establishing the reciprocal obligations of the health care system to health care workers
- establishing a framework to allocate strained resources such as ventilators, antiviral medication, or community health services
- establishing a framework for communicating information to the public

This resource is based on the existing literature summarized above, and recent developments in the COVID-19 pandemic reported in the press as of this writing, including information on vulnerable populations.

Ethical Duties of Healthcare Providers in a Pandemic

Health care workers (HCWs) -- both clinical and nonclinical -- face disproportionate health risks in a pandemic situation. They may face competing personal and professional obligations to their patients, colleagues, employers, family members, and to their own health. In the wake of the SARS outbreak, research published in 2009 revealed that as many as 85% of HCWs reported being unwilling to show up for work in a pandemic (CanPREP, 2009), that was validated by news reports during the 2014 Ebola crisis (Sun, 2014) and now in the several countries first to deal with COVID-19, which was officially declared a global pandemic on March 11, 2020 (WHO, 2020). As of this writing, accurate data surrounding the exact risks to healthcare workers are unclear, but the experiences in China and Italy suggest that 20-30% of exposed healthcare workers are becoming infected. In some countries, reports state that two-thirds of in-hospital transmissions have been due to HCW transmissions (Newsweek, 2020; Yang, 2020; YouTube, 2020).

Pandemic Ethics researchers have raised the following questions: Do HCWs have an obligation to treat patients despite risk of infection? What limits, if any, are there to health care workers' duty to care? What institutional supports are owed to health care workers in a pandemic? Health care workers' ethical duty to care (distinct from the legal duty to treat) is both a professional duty and societal duty, but professional codes are typically insufficient in addressing duty to care in a pandemic. Communicating duty to care to HCWs is best done within the context of societal obligations (a social contract framework) rather than professional obligations, but that reciprocity should be a consideration in priority setting. Research indicates that the public's perception of HCWs is that they have special obligations to care because of the profession they entered, but that their institutions or government must ensure they have reciprocity, meaning they are safe, and fairly compensated for their risk, and given priority for resources. Core guidelines comprise the following, cited verbatim (CanPREP, 2009):

1. *Pandemic planners should ensure the right of HCWs to safe working conditions is maximized to ensure the discharge of duties and that HCWs receive sufficient*

- support throughout a period of extraordinary demands, which will include training on hygienic measures to reduce infection risk.*
- 2. Consideration should be given to needs of health care providers to ensure care to their families.*
 - 3. Professional associations should provide, by way of their codes of ethics, clear guidance to members in advance of a pandemic. This may include information regarding existing mechanisms to inform members as to expectations and obligations regarding the duty to provide care during a communicable disease outbreak.*
 - 4. Pandemic planners should ensure that processes be in place to accommodate legitimate exceptions to the provision of clinical care (e.g. pregnancy, immunodeficiency).*
 - 5. Pandemic planners should assess local circumstances and ensure participation of the community sector in planning of formal and informal care networks and engage clinical and non-clinical, professional and non-professional HCWs.*

A review of hospital policies shared by clinical ethicists at numerous hospitals echo the frameworks above. The Veterans Affairs National Center for Ethics in Healthcare has added the following policy surrounding ***the duty to provide Cardiopulmonary Resuscitation (CPR) to patients with COVID-19*** (Alfandre, 2020):

Generally, health care providers have a duty to provide potentially life-saving treatments to patients, such as CPR, unless it is impossible to adequately mitigate risk to staff. Codes of ethics of all health care professionals include a duty to provide care for patients even at some risk to themselves. This is a primary ethical duty of the health care professional, but it is not absolute and there are ethically justifiable exceptions. Those exceptions occur when there is disproportionate risk to the health care professionals providing the care.

The Endocrine Ethics Association has added the following guidelines specific to COVID-19:

1. Clear institutional or professional association guidelines must be provided regarding self-quarantine, social distancing and reducing assembly for the following groups: (1) HCWs in the hospital; (2) medical faculty who routinely educate through rounding or teaching in small groups or large groups; (3) HCWs and faculty who travel to lecture or attend conferences. Note: When the Endocrine Society cancelled its 2020 conference, and the International Thyroid Congress put its Fall conference on hold, these organizations helped to endorse social distancing as a mitigation strategy.
2. High demand for hand sanitizer, toilet paper, rubbing alcohol, and other products have put a strain on HCWs using such products for essential purposes in the clinical enterprise. Reducing our use of such products can help address this concern, and may be done by employing telecommuting/teleworking for all staff and faculty who are not involved in direct patient-care. Establishing Endocrine Telehealth with appropriate remuneration and Remote Continuing Medication

- Education for endocrine practitioners as normative practice, helps to endorse and support pandemic ethics frameworks that will be in place until sufficient testing or vaccination programs can be established.
3. Specific strategies for groups of endocrine patients should be created by multi-disciplinary task forces to help patients stay safe during quarantine, which should be initiated by major endocrine societies.
 4. Specific programs addressing endocrine practice during pandemics should be developed for trainees (residents, students).
 5. If endocrine practitioners do not feel that infection control measures are adequate for keeping them safe, there should be clear venues within their institutions for them to voice concerns, or they may make use of their professional societies to advocate for their concerns.
 6. Unclear guidelines surrounding testing for COVID-19, combined with a shortage of test kits, have seriously interfered with assessing the scope of the pandemic. The Precautionary Principle approach should be employed, which assumes that there is *prevalent community spread* until/unless antibody testing can be employed to determine immunity. Specific guidance surrounding quarantine measures should be provided to high-risk endocrine patients.
 7. Endocrine colleagues should make use of their institution's clinical ethics consultation service to address both COVID-19 ethics questions or other endocrine ethics questions. (Or, they may consult the Endocrine Ethics Association consult service available to Members.)
 8. Endocrine colleagues should make use of wellness services provided by their institutions to deal with personal stress to maximize professional obligations.

Ethical Frameworks for Allocation of Resources and Priority Setting

“Priority Setting” is the dominant term used by pandemic ethics researchers in the discussion of resource allocation in a pandemic setting, in which ordinary healthcare resources and services demands are expected to exceed supply.

In a pandemic setting, access to: beds, ventilators, sanitizing products, personal protective equipment (PPE: masks, face shields, gowns, gloves), test kits, future vaccines, antivirals, and other necessary resources in hospitals and in the community may need to be prioritized. Clinical criteria are insufficient to address such prioritization. Value-based decisions in a pandemic setting will need to be made, but how? Should we give priority to the sickest or should those most likely to survive be the benchmark? Italy recently faced extreme wartime-like triage decisions. (Lintern, 2020; Mouk, 2020; Newsweek, 2020;), and published its own triage ethics protocol (see Appendix 1).

The following questions have been raised by pandemic ethics researchers (CanPREP, 2009): *Should resources be allocated to save the most lives or to give everyone a fair chance at survival? Should special consideration be given to vulnerable populations in determining access to resources? Who should make these allocation decisions?*

The ethical goals of resource allocation or priority setting are legitimacy, fairness,

and equity. Research indicates the following parameters are acceptable to the public in resource allocation decisions: need, survivability, and social value. Need takes into consideration not just the sickest person; persons who are responsible for caring for others may take priority. Social utility of individuals (healthcare workers, critical infrastructure workers, etc.) who are sick is a key concept in prioritizing. Establishing transparent priority setting criteria in advance of a crisis is another key concept to enforce fairness and public trust in priority setting. There is public consensus that priority should be given to healthcare workers, whose social utility value is high; and whose risk assumption is high. Research indicates there is public consensus that children should be given second priority after healthcare workers. (CanPREP, 2009).

The WHO (2008) emphasizes that priority setting is typically based on the principle of efficiency (saving most lives), which prioritizes protecting individuals responsible for caring for the sick, and is not necessarily based on prioritizing resources for the “sickest.” The principle of equity is typically a failed principle in priority setting because equitable distribution of resources may not achieve the goals of public safety in pandemic situations. The WHO White Paper on priority setting provides a detailed and thorough discussion of the strengths and weaknesses of various moral frameworks for establishing priority setting guidelines, however the 2009 University of Toronto report distills much of this information into practical guidelines, stated here verbatim (CanPREP, 2009):

- 1. Governments and health sector officials should engage the public actively in transparent, inclusive, and accountable deliberations about priority-setting issues related to the use of limited resources for treatment and prevention.*
- 2. Governments and health care sector officials should engage stakeholders (including health care workers and administrators, and the public) in determining what criteria should be used to make resource allocation decisions (e.g., access to ventilators, vaccines, antivirals).*
- 3. Governments and health care sector officials should provide an explicit rationale for resource allocation decisions, including priority groups for access to limited health care resources and services. The rationale should be publicly accessible, justified in relation to the defined criteria, and include a reasonable explanation for any deviation from the pre-determined criteria.*
- 4. Governments and health care sector officials should ensure that there are formal mechanisms in place for stakeholders to bring forward new information, to appeal or raise concerns about particular allocation decisions, and to resolve disputes.*

The Endocrine Ethics Association has added the following guideline specific to COVID-19:

1. In the absence of clear guidance from government institutions, individual institutions must provide transparent criteria for priority-setting for PPE conservation of hand sanitizer, and other products in short supply.
2. Individual institutions should include a bioethics representative in incident-command decisions surrounding resource allocation and rationing, while

- decisions made by professional endocrine organizations should include a bioethics representative in program planning during and post-pandemic.
3. Separate COVID-19 rationing policies should be created for the field of endocrinology by implementing multi-disciplinary task forces to deal with special populations, which also look at early vaccine rationing.

Ethical issues in Triage

The WHO (2008) emphasizes the following with respect to triage, stated verbatim:

Similar to judgments about medical futility, triage decisions should be based upon professional standards that are publicly justifiable. In this way, controversial and deeply troubling decisions are not left to the discretion or subjective assessment of individual caregivers. Priorities should be based upon general triage criteria that are reasonably acceptable to everyone. On the one hand this involves appeal to the basic normative principles discussed previously; maximization of health benefits (notably saving lives) and equity. On the other hand, criteria should be defined and specified on the basis of medical evidence about health needs and factors that determine the chance of recovery.

In critical care, the primary focus is on saving lives by responding to acute health crises. Triage decisions aimed at saving the most lives with limited resources will give less priority to patients who are expected to recover less easily. Although the implications of such decisions will be harsh and controversial, the basic principle to save the greatest number of lives possible can be reasonably justified to anyone.

Appendix 1 lists several resource-allocation policies that reflect the framework above.

Ethical Considerations regarding Quarantine, Mask-Wearing, Sick Leave, Testing and Vaccination: Patient Care

The main issues identified with the American experience with COVID-19 is that since adequate testing has been delayed, containment and mitigation is reliant on self-monitoring for symptoms and self-quarantine from the workplace or other public places. Mask-wearing is another important strategy in mitigation. Additionally, since COVID-19 is asymptomatic or mild in many groups, those who do not have adequate sick pay or compensation may feel compelled to go to work with known exposure to infected individuals or with mild symptoms, despite being contagious, while mask-wearing has become a contentious issue surrounding compliance. As for a COVID-19 vaccine, although challenge trials are underway to speed up the process, it is typically not expected that an appropriate vaccine will be available to the public until 2021 or later (if at all), and for many this will be far too late. Yet even when a vaccine has been developed and approved, deployment will be incremental, likely meet with resistance from people opposed to vaccination, and there will be insufficient initial production capacity to accommodate the enormous worldwide demand. Priority-setting guidelines can help to get vaccines to critical populations. However, there is a considerable ethical issue regarding vaccine refusal.

With respect to non-compliance with self-quarantine or mask-wearing for either short or long periods (which includes not working when sick), it is imperative to provide clear guidelines for patients at risk, who have tested positive, or who have not been tested at all. In the first group, mask-wearing should be imperative regardless of symptoms or status; in the second group, self-quarantine should be imperative, and state intervention is justified to ensure self-quarantine is followed, but sponsored healthcare should be provided for those quarantined. For those who are symptomatic and untested, compensation for missed work should be provided as an incentive to stay home when symptomatic or on self-quarantine. For those who are asymptomatic but exposed to someone positive for COVID-19, self-quarantine combined with compensation for missed work should be provided as above. Endocrine practitioners can help to instill these guidelines by writing medical notes for patients' employers, or to the relevant bodies. Education about mask-wearing is also critical.

Mandated Testing and Vaccination for HCWs

With respect to testing or vaccine refusal, once testing is readily available and a vaccine for COVID-19 becomes available, mandated testing and vaccines for HCWs should become part of the employee health compliance programs and priority should be given to HCWs, and mandatory testing of patients should take place in all endocrine practices.

Testing refusal may be linked to social implications of testing positive for an illness, as seen in the early years of HIV testing, for example. Vaccination refusal is linked to two issues in public health: (1) a flawed vaccine that was distributed in 1976, in anticipation of a flu pandemic, which produced a number of side-effects; (2) parental distrust of vaccines, and their disproven association with autism, based on retracted research by Wakefield et al. in 1998, and retracted in 2010 in the *Lancet*. There is an increasing distrust by the public regarding the safety of vaccines. Refusal of vaccines is also now seen among healthcare workers. Vaccination refusal has been examined by Diekema (2005), and deals with the parental refusal of vaccine in the context of the Harm Principle. Extended to adults, the Harm Principle, as well as the Duty to Warn from the 1976 Tarasoff case (Tarasoff, 1976), is a defensible framework for state/institution intervention to force compliance with testing, quarantine or vaccine in a pandemic event that is a clear threat to human health in which third parties should be protected from community vectors or suspected index patients for various clusters.

Testing, quarantine and vaccines in a pandemic situation not only provide for the benefit of the individual, but also for the benefit of the public. The process of containment (quarantine), or creating "herd immunity" (vaccine) allows for individuals who do not get tested or vaccinated, or cannot get vaccinated, to derive some measure of protection from others in the population being successfully quarantined or immunized.

Determining the purpose of a testing, quarantine or vaccination program is a key concept: is it to protect the public or individual? If it is to protect the individual, then the individual's autonomy to refuse quarantine or vaccination should be honored. However, if the program is designed to protect the public, then the principle of "solidarity" and protecting the public from harm justifies coercive policies in mandating quarantine and vaccination, and infringing upon individual liberty. Such measures have been recently implemented in 2020 in China, Italy, Kentucky, and parts of New York State.

Pandemic ethics researchers assert that in order for public health officials to justify the use of more coercive measures, they need to have scientific evidence that supports the population health benefits of the quarantine or vaccination program. Coercive policies can include consequences for HCWs who refuse to quarantine or get the vaccine. Some work places have introduced laws that require health care workers to go home without pay if they refuse vaccination.

Mandated school quarantine or vaccination programs are also common, as well as mandated quarantine for adults. Coercive policies could be justified to reduce crowd size, such as cancelling live classes, or not permitting school attendance during an outbreak if the student is not vaccinated. While there may be a reluctance to use and justify coercion, public health officials also have a responsibility to justify the lack of use of coercive policies for quarantine or vaccination, particularly if there is evidence for the population health benefits of such policies. The failure to do so would violate the principle of solidarity and protecting the public from harm, resulting in avoidable illness and death. In making this decision, officials will have to balance the potential risks and benefits of the quarantine or vaccination program, taking into account the strength of evidence for both of these.

Officials will also have to be guided by the “precautionary principle,” which advocates a lower evidentiary standard for acting to protect against a large-scale risk than what is traditionally used in evaluating the benefit of health technologies at the individual level.

In any mandated quarantine or vaccine program, there are reciprocal responsibilities of the state to quarantine and vaccine recipients: ensuring job security and compensation for quarantine; ensuring the safety and effectiveness of the vaccine, and providing just compensation to those who suffer an adverse event following vaccination.

With advent of testing for COVID-19 antibodies, evidencing recovery from a prior infection, additional issues arise. To date, it is still not known if the presence of these antibodies confers protection against reinfection. In addition, if and when vaccines become available, it is not yet known whether they will provide temporary or long-standing protection against COVID-19 infection. When those questions are answered, these individuals may be issued “immunity passports” that permit unfettered social interactions. This may unleash a wide range of ethical problems, including: employment discrimination, travel restrictions, social stigmatization, against those without “passports”

Individual Liberty Restrictions and Shelter in Place

Research indicates that roughly 85% of the population supports states and governments to suspend some individual rights (e.g. traveling, right to assemble) during a pandemic, and in extreme. However, such rights can only be suspended in the public’s view, with reciprocity: reciprocal obligation of governments to provide for the basic needs of restricted individuals, as well as support services after the restrictive measures end. For example, restricted individuals should not be penalized by an employer for following a quarantine order (e.g., losing a job). More recently, bioethicists have weighed mitigation strategies against shutting down economies in the context of a “last resort” efforts to reduce transmission. (See: <https://bioethics.jhu.edu/research-and-outreach/covid-19-bioethics-expert-insights/resources-for-addressing-key-ethical-areas/grappling-with-the-ethics-of-social-distancing/>).

Summary

Pandemic Ethics researchers have summarized guidelines as follows, which appear verbatim (CanPREP, 2009):

1. *Public health officials should ensure that pandemic response plans include a comprehensive and transparent protocol for the implementation of restrictive measures. The protocol should be founded upon the principles of proportionality and least restrictive means, should balance individual liberties with protection of public from harm, and should build in safeguards such as the right to appeal.*
2. *Governments and the health care sector should ensure that the public is aware of the rationale for restrictive measures, the benefits of compliance, and the consequences of non-compliance.*
3. *All pandemic plans should include measures to protect against stigmatization and to safeguard the privacy of individuals and/or communities affected by quarantine or other restrictive measures.*
4. *Measures and processes ought to be implemented in order to guarantee provisions and support services to individuals and/or communities affected by restrictive measures during a pandemic emergency. Plans should state in advance what backup support will be available to help those affected by restrictive measures (e.g., food, bills, loss of income). Government should have public discussions of appropriate levels of compensation, including who is responsible for compensation.*
5. *In order to get the public “on board” with decisions regarding restrictive measures, policymakers need to include the public in deliberations about public policy with respect to pandemic influenza.*

*Adapted from *The University of Kentucky Pandemic Ethics Resource*

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Note: The Journal of Clinical Ethics has collected articles that were originally published as "Clinical Ethics in Catastrophic Situations: Mapping a Standard of Care," written after Hurricane Katrina, Guest Edited by Jeffrey T. Berger, MD, FACP, FAAHPM. Articles in this collection include:

Bedside Ethics and Health System Catastrophe: Imagine If You Will . . .

Jeffrey T. Berger, Guest Editor

A Possible Application of Care-Based Ethics to People with Disabilities during a Pandemic

Edmund G. Howe

Family Participation in the Care of Patients in Public Health Disasters

Tia Powell

Sufficiency of Care in Disasters: Ventilation, Ventilator Triage, and the Misconception of Guideline-Driven Treatment

Griffin Trotter

Pandemic Preparedness Planning: Will Provisions for Involuntary Termination of Life Support Invite Active

Euthanasia?

Jeffrey T. Berger

Should Palliative Care Be a Necessity or a Luxury during an Overwhelming Health Catastrophe?

Philip M. Rosoff

Taking Seriously the “What Then?” Question: An Ethical Framework for the Responsible Management of Medical Disasters

Endocrine Ethics Association White Paper Series 2020

Laurence B. McCullough
Legal Briefings: Crisis Standards of Care and Legal Protection during Disasters and Emergencies
Thaddeus Mason Pope and Mitchell F. Palazzo
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Jeffrey T. Berger, Guest Editor
How Can Care providers Most Help Patients during a Disaster?
Edmund G. Howe
An Ethical Framework for the Responsible Management of Pregnant Patients in a Medical Disaster
Frank A. Chervenak and Laurence B. McCullough
Non-Pharmaceutical Interventions to Limit Transmission of a Pandemic Virus: The Need for Complementary Programs
to Address Children’s Diverse Needs
Armand H. Matheny Antommara and Emily A. Thorell
Attending to Social Vulnerability When Rationing Pandemic Resources
Dorothy E. Vawter, J. Eline Garrett, Karen G. Gervais, Angela Witt Prehn, and Debra A. DeBruin

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Appendix 1: Samples of State Pandemic Ethics Plans for Resource Allocation

Arizona:

<https://www.azdhs.gov/documents/preparedness/emergency-preparedness/pandemic-flu/az-pandemic-influenza-response-plan.pdf>

Maryland (used by Daugherty et al. in Chest, 2019, under Additional Reading). PDF only available, and sent to HEC members.

Michigan:

<http://www.mimedicaethics.org/Documentation/Michigan%20DCH%20Ethical%20Scarce%20Resources%20Guidelines%20v2%20rev%20Nov%202012.0.pdf>

Tennessee:

https://www.tn.gov/content/dam/tn/health/documents/2016_Guidance_for_the_Ethical_Allocation_of_Scarce_Resources.pdf

Utah:

http://health.utah.gov/epi/diseases/novel_influenza/plan.pdf

Specific COVID-19 Ethics Rationing Protocols:

Italian Society for Anesthesia Analgesia Resuscitation and Intensive Care (SIAARTI). English version by SIAARTI is here:

<http://www.siaarti.it/SiteAssets/News/COVID19%20-%20documenti%20SIAARTI/SIAARTI%20-%20Covid-19%20-%20Clinical%20Ethics%20Reccomendations.pdf>

The Hastings Center. Ethical Framework for Health Care Institutions Responding to Novel Coronavirus SARS-CoV-2 (COVID-19) Guidelines for Institutional Ethics Services Responding to COVID-19 Managing Uncertainty, Safeguarding Communities, Guiding Practice. <https://www.thehastingscenter.org/wp-content/uploads/HastingsCenterCovidFramework2020.pdf>

Appendix 2: Ethical Framework for Pandemic Preparedness

Adapted from *Ethical Framework for Pandemic Preparedness* (CanPREP, 2009).

Substantive Values

Individual Liberty. In a public health crisis, restrictions to individual liberty may be necessary to protect the public from serious harm. Restrictions to individual liberty should:

- be proportional, necessary, and relevant;
- employ the least restrictive means; and
- be applied equitably.

Protection of the public from harm. To protect the public from harm, health care organizations and public health authorities may be required to take actions that impinge on individual liberty. Decision makers should:

- weigh the imperative for compliance;
- provide reasons for public health measures to encourage compliance; and
- establish mechanisms to review decisions.

Proportionality. Proportionality requires that restrictions to individual liberty and measures taken to protect the public from harm should not exceed what is necessary to address the actual level of risk to or critical needs of the community.

Privacy. Individuals have a right to privacy in healthcare. In a public health crisis, it may be necessary to override this right to protect the public from serious harm.

Duty to care. Inherent to all codes of ethics for health care professionals is the duty to provide care and to respond to suffering. Health care providers will have to weigh demands of their professional roles against other competing obligations to their own health, and to family and friends. Moreover, health care workers will face significant challenges related to resource allocation, scope of practice, professional liability, and workplace conditions.

Reciprocity. Reciprocity requires that society support those who face a disproportionate burden in protecting the public good, and take steps to minimize burdens as much as possible. Measures to protect the public good are likely to impose a disproportionate burden on health care workers, patients, and their families.

Equity. All patients have an equal claim to receive the health care they need under normal conditions. During a pandemic, difficult decisions will need to be made about which health services to maintain and which to defer. Depending on the severity of the health crisis, this could curtail not only elective surgeries, but could also limit the provision of emergency or necessary services.

Trust. Trust is an essential component of the relationships among clinicians and patients, staff and their organizations, the public and health care providers or organizations, and among organizations within a health system. Decision makers will be confronted with the challenge of maintaining stakeholder trust while simultaneously implementing various control measures during an evolving health crisis. Trust is enhanced by upholding such process values as transparency.

Solidarity. As the world learned from SARS, another pandemic outbreak will require a new vision of global solidarity and a vision of solidarity among nations. A pandemic can challenge conventional ideas of national sovereignty, security or territoriality. It also requires solidarity within and among health care institutions. It calls for collaborative approaches that set aside traditional values of self-interest or territoriality among health care professionals, services, or institutions.

Stewardship. Those entrusted with governance roles should be guided by the notion of stewardship. Inherent in stewardship are the notions of trust, ethical behavior, and good decision-making. This implies that decisions regarding resources are intended to achieve the best patient health and public health outcomes given the unique circumstances of the influenza crisis.

Procedural Values

Reasonable. Decisions should be based on reasons (i.e., evidence, principles, and values) that stakeholders can agree are relevant to meeting health needs in a pandemic influenza crisis. The decisions should be made by people who are credible and accountable.

Open and transparent. The process by which decisions are made must be open to scrutiny, and the basis upon which decisions are made should be publicly accessible.

Inclusive. Decisions should be made explicitly with stakeholder views in mind, and there should be opportunities to engage stakeholders in the decision-making process.

Responsive. There should be opportunities to revisit and revise decisions as new information emerges throughout the crisis. There should be mechanisms addressing disputes/complaints.

Accountable. There should be mechanisms in place to ensure that decision makers are answerable for their actions and inactions. Defense of actions and inactions should be grounded in the 14 other ethical values proposed above.