Bioethics & COVID-19: Guidance for Clinicians

(1st Edition)

Malaysian Bioethics Community

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EDITORS' NOTES

Dear Readers,

Hi there! Thank you for using "Bioethics & COVID-19: Guidance for Clinicians". This guidance is focused on clinical ethics and has been compiled with Malaysian clinicians and clinical decision-makers in mind.

Objectives

The main objectives of the guidance are to support clinicians in making ethical decision in their clinical practice when responding to the COVID-19 situation in Malaysia, and to encourage a thoughtful process through open and inclusive discourse when faced with some of the most challenging ethical issues they will encounter.

The specific objectives are:

1. To assist clinicians in transitioning from the clinical care/practice they provide on a typical day (patient or family-centred focused) to a redefined clinical care/practice provided during a pandemic (public health-centred).
2. To ensure that clinical care is not jeopardized to a harm threshold during a public health crisis, and most importantly, that compassionate care and healing could take place.
3. To support ethically acceptable practices in clinical care for a pandemic

Theme and Scope

Clinical Ethics remains the **main theme** of this guidance with topics that are related to the fiduciary obligations to patients and families, trust and relationships, compassionate care, end-of-life care, and clinician's well-being.

Duty-based Professional Ethics and Public Health Ethics will be covered **to a certain extent,** and although the information provided may serve as a good reference to clinicians and policymakers, they do not intend to make legal claims on responsibilities and risks.

Contents

This guidance, a compilation of contributions from 23 individuals, is unique by local and international standards. Most ethical guidelines published at this point have been ethics-loaded, generic, and not Malaysian-focused. The choices of topics for this guidance are based on the months-long observation of the COVID-19 situation in Malaysia, and the direct feedback from local clinicians. Many of the contributors are senior clinicians themselves.

Bioethics is a wide and varied field, and while attempting to keep the document reader-friendly and easy engagement by clinicians, we have tried to retain the individual writing styles of each contributor and the depth of content provided by them in each chapter. This was to say the least, a tough balancing act, and was only manageable

through numerous thoughtful deliberations among the contributors as part of the Malaysian Bioethics Community and its initiatives. We would therefore like readers to kindly take note of the following:

1. **Definitions**
   - Physicians/Surgeons = Doctors.
   - Clinicians = Bedside healthcare professionals that are directly involved in the care and decision-making of the patients, such as doctors and nurses.
   - Healthcare workers (HCW) or healthcare providers (HCP**)** = Individuals that deliver care directly or indirectly to patients, such as doctors, nurses, pharmacists, medical assistants, medical attendants, physiotherapists, occupational therapists, lab technicians, and medical waste handlers.
2. **Case scenarios,** in the form of narratives, are meant for moral imagination and triggers for further conversations. The stories told here are fictional or semi-fictional, and are in no way related or associated to a particular patient. They are related to common clinical scenarios and as such any relation of the details to particular patients are of mere coincidence.
3. **Original ideas or proposals** are usually labelled as "Proposed", "Suggested", or "Recommended" with no references included.

General Guide for Reading

Reading the guidance from beginning to end would be ideal, however, we would advise that you refer to the Table of Contents if you should wish to focus your attention of only particular topics of interest to you. The aims for the different sections are illustrated here:

Section 1 on Public Health Ethics, Health Policy and Governance gives one an overview of the public health impetus, clinical governance, social implications of COVID-19, two published ethical frameworks on resource allocation, and resonates with both clinicians and healthcare leaders and serves as a background read to the subsequent sections.

Section 2 on Professional Ethics covers areas of professionalism and duty-based ethics that will complement what is available from the ethical guidelines from MMC and MOH.

Section 3 on Clinical Ethics and Decision-Making lays out the ethical challenges in clinical decision-making and clinical care, and the ethical acceptable approaches or alternatives that could be considered and reflected upon by clinicians. There will be an overview of the roles of clinical ethics services, that will be relevant to both clinicians and healthcare leaders.

Section 4 on Ethical and Compassionate Approaches further elaborates on the ethical and compassionate steps that are practical for clinicians to consider in the care of their patients during a pandemic. This section also dives into the topic of moral distress with a pandemic-focused and how to ensure the well-being of clinicians.

Section 5 on Research Ethics and Other Ethical Reflections include the bonus addition of the important topic on the justification of research during the pandemic and its relation to clinical care, and other interesting essays and reflections that hope to attract the readers awareness and attention.

Feedback

Lastly, we hope that you enjoy reading this guidance, which intends to facilitate difficult conversations and assist clinicians in any way possible. If you have any queries, comments or feedback, this can be sent to: ethicsmalaysia@gmail.com

Similarly, should you face any ethical challenges in your clinical practice, you can utilise the Clinical Ethics Malaysia (CEM) COVID-19 Consultation Service by visiting the following link: https://tinyurl.com/CEMConsultForm.

Happy reading.

HS and Mark

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Appendix

CHAPTER 1

Original Bioethics Guidance For COVID-19 In Malaysia

Tan Hui Siu, Sharon Kaur, Mark Tan Kiak Min

The following essay was shared on 20th March 2020 and is reproduced in its entirety with permission as below:

BIOETHICISTS have been following the progress of the COVID-19 pandemic very closely since January 2020. Public health officers and healthcare providers are on the frontlines of this ever-changing situation, where they have to adapt daily to allocate resources, mobilise the workforce, and coordinate services. Science alone is insufficient as we face many uncertainties. The structural elements of social capital, healthcare system, and governance, are key to successfully navigating the COVID-19 pandemic. In carrying out their mandate, policy-makers and decision-makers will be forced to consider competing ethical values. We believe that there is a need to address several critical ethical issues that have or will arise as a result of this pandemic -- specifically, the tensions between public health interests and personal rights and freedom; the importance of shared responsibility, trust and trustworthiness; and the crucial role of ethical guidance and resolution.

A. INTERSECTION OF PUBLIC HEALTH, HUMAN RIGHTS, GOVERNANCE, AND THE PEOPLE

1. Tensions Between Public Health Interests And Personal Rights And Liberty

Public health measures in containing the spread of the virus at this moment must be applauded. Isolation, quarantine, contact tracing, thermal scans, resource mobilization are some of the coordinated efforts the healthcare policy-makers and providers are working on. A mitigation phase must be instituted as soon as possible to reduce the further impact on the healthcare system and the socioeconomy. The healthcare system can be overwhelmed by cases that have drastically increased from inadequate community effort to social distance, reduce travel, and comply with public health authority's advice.

Restriction of the rights and freedoms of individuals are scientifically and ethically required to contain the spread of infectious disease. Measures must be put into place to ensure that people are treated with dignity and that certain populations such as the elderly, the poor, students, migrant workers do not bear a disproportionate burden of the risk. Human rights is an ethical principle for self-protection from oppression and discrimination, but also self-justification used by individuals against the restriction of their personal freedom, misperceived breach of privacy and confidentiality, stigmatization, and the fear towards the pandemic and unfamiliar public health interventions. These human sentiments can be countered by showing that confinement works and is needed. Confinement could be humane and free from stigma by having the basic necessities and psychosocial support provided for people

who are confined. Apart from the need to contact trace and containment, healthcare providers must show that privacy and confidentiality are protected at all times, even under socio-political pressure. The choice between collective goods and individual interests does not need to be sharp trade-offs but could be a good synergy during public health interventions(1).

Mandatory measures like a lockdown should only be instituted if voluntary measures with isolation, quarantine, complying to contact tracing, and social distancing have not been successful(2). Nevertheless, a middle pathway could be adopted by setting mandatory restrictions for mass gathering and schools and office closure for a temporary period as necessary -- to bring the least burdensome/restriction to individuals in the process of addressing the risk and needs of the public. The implementation of lockdown requires thorough planning and full consideration of psychosocial and economic impact.

2. Shared Responsibility

When there are tensions between public health and individual interest, a shared responsibility model, which focuses on healing and constructive ways forward without blaming and retribution, is something that we should adopt during a pandemic crisis like COVID-19.

The Healthcare and Public Health teams are playing their role but will be overwhelmed. They need more help in public engagement, risk communication, effective public health measures enforcement, and also free flow capital support for experts and health care workers to work smoothly and not overburdened. Public health officers and healthcare providers are morally obligated to work as a team and to exhaust the highest level of medical/scientific expertise to ensure the provision of care is adequate and scientifically sound. Healthcare leadership must work closely and be the strongest advocates for the healthcare providers and also the people they serve when they communicate with national leaders.

The People must maintain calm and morally obligated to each other. They must observe their health and safety during the pandemic, and advocate for collective measures, correct information, and solidarity through social media and communal groups. All persons need to come forward to be screened and managed and to be able to lend assistance to the community.

The Government needs to step in quickly and aggressively to lead coordination between the healthcare system, relevant ministries and sectors, and the people during the pandemic. They hold the highest level of obligation to put aside political interests and to work with public health authorities, the people, and all other stakeholders to reach many consensuses, balancing between the needs of pandemic containment, the health of the people, and the socioeconomic impact. They need to work on ways to sustain and reboot all systems later. They need to ensure the sufficiency of public health laws and their enforcement. Decision-makers must ensure that trust is not lost and that systems are trustworthy. Political tensions may jeopardise trustworthiness. Trustworthiness might be at risk if decisions made cause further stress in an already strained system.

3. Trust and Trustworthiness

In a spiralling health crisis like the COVID-19 pandemic, trust and trustworthiness are essential for the implementation of various public health control measures, especially in a socioculturally diverse community. Trust is earned and proven. Trustworthiness is internally driven and virtuous. Trust is strengthened by upholding transparency and inclusiveness. These are some of our observations:

Within the healthcare system, there is already steady teamwork and trust between the healthcare providers under the leadership of the DG, public health, and infectious disease specialists of the Ministry of Health, with the private practitioners and university hospitals. This must be acknowledged and maintained at all times.

Between the MOH and the people, trust has been overall good with a mixed response in some quarters. It could be further strengthened by having more transparency, inclusiveness (e.g., communication through personnel of different languages and background), and to invite the people or relevant stakeholders for meetings, and to continue mass scientific education through broader media like national TVs, newspapers, and school and community announcement.

Between the government and the people, trust has been weak, and there is no way but to rope in good brokers, e.g., previous administrators, sociologists/group/religious leaders to step in to mediate efforts and to ensure seamless continuity of efforts and communication. As a government, good governance, transparency, and accountability are the keystones to build long-lasting trustworthiness. This should include:

1. Transparency and accountability - open communication is key, and effective alternative communication strategies should be explored to ensure that vulnerable populations such as the elderly, migrant workers can access accurate and up to date information. Lines of responsibility and accountability should be clear and transparent.
2. Good governance - Processes should be put into place that promote efficiency, effectiveness, and ethical decision making. All key stakeholders should be included regardless of political, religious, or community affiliations.
3. Supporting frontline workers by among other things, providing safe work environments, assistance for family members and moral support

B. ANTICIPATORY ETHICAL PRINCIPLES AND GUIDANCE

Ethical or legal frameworks for pandemics in the country are not available. Hence, the WHO 2016 “Guidance for Managing Ethical Issues in Infectious Disease Outbreaks(5)” is a useful reference and recommends the establishment of an emergency ethics taskforce/bioethics commission to take it from where we are now, to be part of the concerted public health effort. At the hospital level, a hospital ethics committee or clinical ethics consultation will be helpful to resolve ethical dilemma as listed below; and mediate disputes at the patient-physician or organizational level. An ethical front and deliberation is important to develop more moral spaces in the institution or organisation, address moral distress and burnout of staffs, and create a more reflective society.

Ethical Issues and Values

A firm decision is needed if **voluntary public health measures** for individuals need to be replaced by mandatory actions when the significant infectious and health **risks to the public health** overall are imminent. These health risks are not only about COVID-19, but also other non-COVID-19 diseases when their care and management would be deprioritized and affected to a significant extent.

According to Smith and Upshur(3), the ethical principles - **egalitarian/utilitarian/prioritarian** that are used for **priorities settings** for the allocation of health care resources, "should be outlined at the individual level (e.g., triage of a patient to a hospital bed), the organizational level (e.g., service/financing priorities in health care organizations), and the population level (e.g., priority groups for testing and treatment)". Decision-makers need to be **transparent and inclusive** during the engagement with stakeholders, to answer the "how, when, where, and what" of resource allocation, and to ensure **justice** is served.

Acknowledging co-existing **health disparities** and **social inequities**, and **prioritizing vulnerable groups** (old, young, poor, women, mentally ill, marginalized) in specific ways to mitigate the impact and burden on them are ethically essential(4). Their **voices must be heard** through the involvement of their group leaders and be accounted for in any health system decisions or reviews.

The priority in preserving the stability of the healthcare system could be met by ensuring **reciprocal obligations towards our healthcare providers** who are taking that extra risk or **supererogatory role** to contain the pandemic for public health interest. We must give them adequate tools (personal protective equipment, ventilators, drugs) for them to perform containment efforts and clinical management safely. As a community, we need to work on flattening the curve of the pandemic so that the healthcare system has time to cope and function optimally. The **competing obligations** healthcare providers have towards patients (beneficence), their families, and themselves must be recognised and addressed adequately through clear descriptions of their roles and obligations, and the support that they will receive. This applies to **both public and private health facilities.**

The **ethical dilemma** that healthcare providers face should be anticipated and **ethical priorities planned in advance** so that **clinical decisions at the hospitals** are not made on an ad hoc basis as much as possible, under time constraint, socio-political pressure, and **individual rights to care**. The line of instructions follow the lead from public health officers, infectious diseases authorities, and clinical heads during pandemics, of which some ethical issues may include:

1. **Screening criteria challenges** -- to what extent the criteria for PUI/contact should be modified or prioritised given the limitation of resources like PPE, test kits, beds.
2. **Bedside rationing/ICU beds triaging issues** -- should criteria be based on age and prognosis; and the tensions between COVID-19 versus non-COVID-19 prioritisation.
3. **Revision of the standard and level of care** for non-COVID cases during the mitigation phase – the good and bad implications of allowing non-specialist

management of cases, revised admission and discharge criteria, and different treatment threshold due to the limitation of resources.

4. **Prioritising services** during the mitigation phase -- the immediate and long term health and systemic impact of cutting down elective or non-urgent cases.
5. **Mobilisation of the workforce** -- the changes in job descriptions for healthcare providers with different skillset and the involvement of junior providers.
6. **The differences of personal opinion** on when a resource should or should not be allocated to a particular individual -- the **moral distress** that comes along, which needs clear clinical and ethical resolution pathway.

C. CONCLUSION

Ethical input and support could be involved during decision-making, policy-making level, implementing stage, or even at the individual physician-patient level, concerning the hardest of hard decisions during a pandemic. **It is crucial to identify conflicts as early as possible, to mitigate any potential disruption to coordination to care, relationships, and trust, and to ensure justice, transparency, and accountability are observed. Thoughtful deliberation and decision-making is crucial.** We hope this document offers some ethical directions and raise the awareness of the ethical issues for all that are working relentlessly to provide a just and highest level of care during the trying time of COVID-19.

D. ADDITIONAL MATERIAL

Ethical Principles in Priority Settings for Public Health

Definitions and explanations adopted from these resources: 1. “Pandemic Disease, Public Health, and Ethics” by Maxwell Smith and Ross Upshur, from the Oxford Handbook of Public Health Ethics, September(1) 2. Stanford Encyclopedia of Philosophy(6).

- **Egalitarian**

“This principle aims to give individuals an equal chance to benefit from available resources, either through a lottery or through a first-come, first-served system. However, it has been criticised for ignoring information that many believe ought to be relevant when allocating valuable resources (such as an individual’s need)(1).”

- **Utilitarian**

Utilitarian aims to maximize benefits for the largest population. “Allocating resources that aims to save the most lives possible or to maximize the total number of life years or quality-adjusted life years (QALYs) saved is a principle of this sort(1).” Maximizing principles have been criticized for not considering the worst off or the fair distribution of benefits and burdens(1).” On a subcategorization, rule-utilitarian acknowledges the need to comply with moral rules but utility is still the core underpinning principle and moral rules are secondary.

- **Prioritarian**

This principle requires the allocation of resources first to the sickest or vulnerable individuals (i.e., children). "However, these principles generally countenance the allocation of resources to the worst off even when only minor health gains are possible, even when they come at high costs. This type of fairness requires that special attention be given to particular individuals or populations that are vulnerable due to biology, social disadvantage, or another form of disadvantage. Sometimes, this fairness also sets the priority to those who are perceived as being instrumental to a successful pandemic response, such as health care workers(1)."

- **Deontology**

The term deontology is derived from the Greek deon, "duty," and logos, "science", of which an action is considered morally good because of the characteristic of the action, and not the product is good, as in consequentialism (utilitarianism is one type)(6). Immanuel Kant was the first great philosopher to define deontological principles. "Kant held that nothing is good without qualification except a good will, and a good will is one that wills to act in accord with the moral law and out of respect for that law rather than out of natural inclinations(7)."

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CHAPTER 2

Clinical Governance And Ethics During The COVID-19 Pandemic

Sheila Gopal Krishnan, Azanna Ahmad Kamar

Clinical governance is a systematic approach that encompasses three key principles(1):

1. "High standards of care,
2. Transparent responsibility and accountability for those standards, and
3. A constant dynamic of improvement"

Several technical components of clinical governance that need to be emphasized during a pandemic would be:

1. Health, Safety, and Staff management

- This is established through communications and policies designed to protect staff wellbeing and act responsibly to slow the spread of COVID-19.
- Systems to monitor efforts of COVID-19 containment must be in place and accessible. They are thereby protecting the personal health and safety of HCP (and their families), the patients, and the public at large.
- Clinical leaders need to consider how to mitigate the impact of sick or quarantine absences as well as closures of certain vital clinical areas within the hospital.
- Careful planning with timely response will be required to ensure that the "right staff" is deployed into the "right place."
- Accountability and transparency are two values that are sought of clinical leaders in the protection of healthcare staff. Ethical leadership requires one to be transparent of effects of the pandemic to healthcare staff and ensure accountability of the actions taken. Examples include:
    - Accountability to protect staff by ensuring adequate access to personal protective equipment (PPE).
    - Transparent regarding distribution of healthcare equipment and the numbers of frontline healthcare workers who directly handle the pandemic.

2. Risk/Crisis Management

- During this challenging time, the staff looks to the leader to take timely, swift, and decisive action when necessary.
- Consider whether an up-to-date crisis management plan is in place and sufficient.
- A well-designed plan assists the hospital/department/unit to react appropriately and not under- or over-reacting, with careful justifications of each plan made. Elements of an effective crisis management plan include:

a) **Contingency plans.** A crisis is inherently unpredictable. However, the department should endeavour to anticipate all potential crises to which it is vulnerable and develop contingency plans to deal with those crises to minimize on-the-fly decision-making. *Examples of scenarios to prepare for: What will our response be if there is a confirmed case of COVID-19 admitted? How will we notify all staff of a confirmed case, and what privacy implications do we need to consider? What planning (e.g., IT training) is required if we need to mandate that our staff works from home or in shifts?*

b) **Thoughtful communications.** The clinical department should oversee the communication strategy. Strategy include supporting communication of risks by upholding inclusivity with the engagement of staff and community. Clear communication and planning within the crisis response team allows effective communication internally and externally, calmly and thoughtfully, which helps build the confidence of all involved during a volatile situation. *Examples of scenarios to prepare for: What will our response be if there is an unprecedented exposure of staff handling a confirmed COVID-19 patient? How will the leader react if a member of staff refuses to work in a COVID-19 ward?*

c) **Accurate clinical documentation and data sources.** This facilitates reflection and studies to improve care during the pandemic or the future. An emergent creation of data registries of cases may be unprecedented. However, its creation should still adhere to basic data protection rules. Storage of what is deemed "contaminated notes" may be difficult. There should be in place, measures undertaken to ensure that these are stored without any destruction of valuable clinical data.

d) **Person risks and emergency succession plans:** Consider whether an up-to-date emergency succession plan is in place that identifies a person who can step in immediately as an interim Consultant/Specialist in the event the main person contracts COVID-19. Consider the need to implement similar plans for other key persons within the department. Communicate this effectively to the identified person.

3. Strategic Opportunities.

Establishments must be sensitized that pandemics create opportunities for research that is invaluable for future pandemics and growth.

4. Aftermath & Audit

- The changes in clinical practice/ behaviour occasioned by the pandemic might have potential lasting effects, for example, decision flow of "who gets the last ventilator."
- It is pertinent that the establishment takes the effort to assess the handling of the situation and identify the "lessons learned" and actionable ideas for continuous improvement to be better prepared for the next pandemic.

5. Ethics and Clinical Governance

- "Good governance requires ethical cornerstones such as accountability, responsibility, probity, and representativeness. However, attempts to examine the link between the good governance and ethical values is scarce internationally(3)."
- Translating and incorporating these ethical principles into action and making a humane clinical decision can be a gargantuan task to achieve in a resource-constrained health service during a Pandemic such as the COVID-19.
- There will be tensions between the aspirations of ethical principles and the reality of health care service delivery at the ground level. Therefore there is an urgent need to create space for discussions of the ethical values and principles that underpin and guide the delivery of humane health care, and the time is now.

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CHAPTER 3

Social Impact Of COVID-19 On Vulnerable Groups

Erwin Khoo Jiayuan, Azanna Ahmad Kamar

The Coronavirus Disease 2019 (COVID-19) outbreak raises unique ethical dilemmas because it makes demands on society from all sectors of life in Malaysia and across the globe. Khoo EJ in an essay published(1) asserted that health professionals must deal with decisions about the allocation of scarce resources that can eventually cause moral distress and may affect one's mental health. Everybody must deal with restrictions on freedom of movement that have shut down whole economies in an attempt to flatten the epidemic curve. In due course, some will question the ethics behind the search for effective treatments and the development of vaccines in a time of uncertainty and distress. Moving forward, these guidelines help us deal with the many questions we have. These sorts of predicaments – and the people that they effect – are very different(1). For many, including health care professionals, the lasting implications of the pandemic have yet to become apparent.

Quarantine, travel restrictions advisory, and authorised measures to reduce transmission such as school and work closure can cause loneliness, confusion, anger, frustration, boredom, and a constant feeling of inadequate information(2). While these measures are justified to safeguard the best interests of society, they impose a significant burden on individuals and indirectly violates the fundamental human rights of freedom of movement.

Reports have shown increased domestic violence and even alcohol abuse during the quarantine. Children are at risk, simply because they are powerless. Effective and empathetic communication is key. Appeals to altruism might mitigate some of these problems. Strategies and social awareness should be put in place to offer support and protection to minimise such risk to children and women(1).

The COVID-19 pandemic is a stark reminder of the divide that exists in societies, between those who can afford 'working from home' and those who cannot and may be forced into poverty as a result(3). Good hygiene practices such as effective handwashing and physical distancing are effective means to flatten the curve and reduce the economic burden. In poorer parts of the country, especially among the urban poor housed within a crowded people's housing project ("Projek Perumahan Rakyat/PPR) low-cost flats, and those in rural East Malaysia, these simple measures may not even be feasible.

Whilst we focus on saving lives, an economic collapse is a catastrophic health risk, too. Access to healthcare will be a heightened concern for those in financial hardship, especially as the pandemic brings additional risks for less secure workers(3). Many companies have instructed staff to work from home, but for many individuals, especially the daily wage earners, this is not an option. Eventually, the pandemic will economically impact everyone with a resultant increase in the numbers and categories of those deemed vulnerable. With a global recession being imminent, the challenge is to ensure that these restrictive measures do not lead to marginalisation and consequentially, widening the social and healthcare disparity.

Ethical leadership requires one to examine the impact of such restrictive measures to the numerous vulnerable groups. A collective effort is required to explore the population's multiple layers of vulnerability in order to safeguard healthcare delivery and avoid worsening of existing health inequities. Identification of these vulnerability layers not only exposes the inherent health risk factors but considers and stratifies the vulnerabilities of the various age groups, the population's pre-existing social vulnerabilities as well as the added socioeconomic vulnerabilities; those of which, may have resulted from the restriction orders.

Zoonotic diseases will continue to pose a threat to humanity with imminent potential for panic and fear that disrupts our everyday lives. Today, we witnessed solidarity(1). We are slowly coming together as one to collaborate, coordinate, share lessons, and help one another. Working together for the good of the country is a fundamental need. Protecting every layer of vulnerable populations is a fundamental obligation. What we must not do is to politicise the situation and blame one another in this time of uncertainty. Until every nation is safe, no nation will be safe.

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CHAPTER 4

Literature Review On The Ethical Framework For Resource Allocation

Wong Jian Yao

Introduction

With the rapidly emerging number of cases and deaths, the World Health Organization (WHO) has recently declared the outbreak of COVID-19 as a pandemic. This raises some ethical concerns in terms of resource scarcity that may happen as a consequence of the current healthcare system being overwhelmed by the increasing number of patients. The Ministry of Health of Malaysia has been proactively sourcing for more medical supplies such as ventilators and PPE, from various sectors locally and internationally. Efforts like enforcing the movement control order and online public health education have been made to "flatten the curve". Although the country is currently coping well with the situation, we should always be prepared for the worst. The articles by Emanuel et al. and Truog et al. have described the potential issues that may arise from resource scarcity during a pandemic, with relevant ethical framework. They have been summarised below for your convenience of quick reading.

Article 1: "Fair Allocation of Scarce Medical Resources in the Time of Covid-19" by Ezekiel J Emanuel, Govind Persad, Ross Upshurtou et al.

This article was published on March 23, 2020, by the New England Journal of Medicine (NEJM)

The COVID-19 pandemic would likely overwhelm the health care infrastructure and necessitate rationing medical equipment and interventions.

Health Impacts of Moderate-to-Severe Pandemics

- The U.S. HHS Pandemic Influenza Plan (2017) modeled the potential public health impact of moderate and severe influenza pandemics; while the COVID-19 pandemic model is based on data from China and Italy.
- If an infected person spreads the SARS-CoV-2 to at least two others averagely, a conservatively low estimate is that 5% of the population could become infected within 3 months.
- A China analysis suggests that only 20% of those infected requires advanced medical services.
- Overall mortality ranges from 0.25% to as high as 3.0%; that is substantially deadlier than seasonal influenza, which has mortality of roughly 0.1%.
- Case fatality rates are much higher for vulnerable populations e.g. older than 80 years, CVD and DM.

Health System Capacity

- Ventilator use is limited not primarily by the availability of ventilators, but rather the number of operators i.e. respiratory therapists and trained critical care staff.
- Diagnostic (tests), therapeutic (drugs, convalescent serum), and preventive (vaccine and PPE) interventions will be scarce, as a result of increasing demand, and technical/governmental failure.
- Flattening out the epidemic curve is crucial
    1. To avoid shortage of hospital beds, ICU beds, and ventilators.
    2. To address the issues in medical workforce (given that medical staff are becoming ill or quarantined).
    3. To overcome resource scarcity in geographical areas with large outbreaks.
- Curve flattening could be achieved with various public health measures e.g. social distancing, cough etiquette and hand hygiene.

Table 1: FOUR Fundamental Ethical Values for Rationing Health Resources in a Pandemic

Maximizing the benefits by saving most lives or most life-years.	**Equal treatment** through random selection of patients
Promoting and rewarding instrumental value by prioritizing patients who can save others, or who have saved others in the past.	**Giving priority to the worst off** by prioritizing the sickest or the younger who will have lived the shortest lives if they die untreated.

NB: No single value is sufficient alone to determine which patients should receive scarce resources. An adaptive multi value ethical framework is required.

SIX Recommendations for Allocating Medical Resources in the COVID-19 Pandemic *(ethical values are in bold)*

1. **Maximize benefits**
    - Emphasizes responsible stewardship of resources.
    - Aim at both saving more lives (population; utilitarian) and more years of life (individual; non-utilitarian).
    - The former aim is justifiable by the limited time and information in a COVID-19 pandemic; while the latter aim becomes subordinate, all patients are encouraged to document in an advance care directive.
    - Prioritises people who are sick but could recover if treated.
    - **Prioritises those who are worst off** in the sense of being at risk of dying young and not having a full life.
    - Helps in reducing the need for withdrawal of interventions anytime later, as it has been overcome with initial bed and ventilator allocation according to the value of **maximizing benefits.**

2. **Prioritize health workers**
   - Front-line health care workers particularly whose roles are irreplaceable in time of crisis **(instrumental values)**, should receive the critical interventions first.
   - This is a form of recognition to their assumption of the high-risk work of saving others, and it may also discourage absenteeism.
   - This must not be abused by prioritizing wealthy or famous persons or the politically powerful above first responders and medical staff.

3. **Do not allocate on a first-come, first-served basis**
   - For patients with similar prognoses, **equality** should be invoked and operationalized through random allocation e.g. a lottery.
   - First-come, first-served is used for long-standing scarce resources (e.g. transplantable kidneys) in which patients can survive without the scarce resource.
   - Crowding and violence can be avoided with this operationalisation.
   - This is also **fairer** to the people who get sick later, perhaps because of their strict adherence to recommended public health measures.

4. **Be responsive to evidence**
   - Prioritization guidelines should differ by intervention and should respond to changing scientific evidence e.g. preventive vaccination is prioritised for elderly (but after critical workers) given they may suffer worse COVID-19 outcomes. **(maximizing benefits)**
   - **Equality** supports using random selection among highest risk categories (over 60 years of age or with coexisting conditions) when vaccine supply is insufficient.
   - Invoking **instrumental value** justifies prioritizing younger patients for vaccines only if epidemiologic modelling shows that this would be the best way to reduce viral spread and the risk to others.
   - Reservation of coronavirus testing for public health surveillance could improve knowledge about COVID-19 transmission and treatments to **maximize benefits.**
   - Considering prognosis, as to **maximize benefits,** higher priority of intensive care (ICU beds and ventilators) access may be set to younger patients with severe illness than to elderly patients.
   - Allocation of antivirals and other experimental treatments to the seriously but not critically ill group, in response to scientific evidence, would **maximize benefits**; the same goes to treatments that are preferentially allocated to patients who would fare badly on ventilation, may produce the **most benefit**.

5. **Recognize research participation**
   - Researchers who are actively seeking for cure, should receive priority for COVID-19 interventions
     as a reward **(instrumental value)**.
   - This will consequently encourage other patients to participate in clinical trials.
   - Research participation should only serve as a tiebreaker among patients with similar prognoses **(equality)**.

6. **Apply the same principles to all COVID-19 and non–COVID-19 patients**
   - Absolute scarcity **equally** affects all patients (heart failure, cancer etc.); fair allocation of resources that prioritizes the value of **maximizing benefits** applies.

Implementing Rationing Policies

1. Fair and constant procedures must be transparent.
2. Prioritisation guidelines should guide individual physicians to carry out fair allocation procedures while handling different cases.
3. Triage officers (not involved in direct patient care) or a triage committee (experienced physicians and ethicists) to help in execution of rationing.
4. Appeal processes (limited to concerns about procedural mistakes) may be incorporated.

Table 2. Ethical Values to Guide Rationing of Absolutely Scarce Health Care Resources in a Covid-19 Pandemic.

Ethical Values and Guiding Principles	Application to COVID-19 Pandemic
Maximize benefits	
Save the most lives	Receives the highest priority
Save the most life-years — maximize prognosis	Receives the highest priority
Treat people equally	
First-come, first-served	Should not be used
Random selection	Used for selecting among patients with similar prognosis
Promote and reward instrumental value (benefit to others)	
Retrospective — priority to those who have made relevant contributions	Gives priority to research participants and health care workers when other factors such as maximizing benefits are equal
Prospective — priority to those who are likely to make relevant contributions	Gives priority to health care workers
Give priority to the worst off	
Sickest first	Used when it aligns with maximizing benefits
Youngest first	Used when it aligns with maximizing benefits such as preventing spread of the virus

Article 2: "The Toughest Triage – Allocating Ventilators in a Pandemic" by Robert D. Truog, Christine Mitchell, and George Q. Daley.

This article was published on March 23, 2020, by the New England Journal of Medicine (NEJM)

A life-or-death choice

- Mechanical ventilation is the most problematic medical care component to be rationed.
- Patients who breathing deteriorates to the point that they need a ventilator, can be saved typically only by initiating mechanical ventilation within a limited time.
- Fully ventilator-dependent patients die within minutes if their machine is withdrawn.
- Decisions to withdraw ventilators for rationing in a pandemic cannot be justified in either of these ways:
  a. It is not being done at the request of the patient or surrogate.
  b. The absolute futility of a treatment that is being claimed.

Goals in rationing

- To save the most lives possible in a time of unprecedented crisis.
- To mitigate the enormous emotional, spiritual, and existential burden to which caregivers may be exposed.

Rationing mechanical ventilators by a triage officer or a triage committee should be composed of (Figure 1)

- People who have no clinical responsibilities for the care of the patient.
- Volunteers who are respected clinicians and leaders in the medical community.

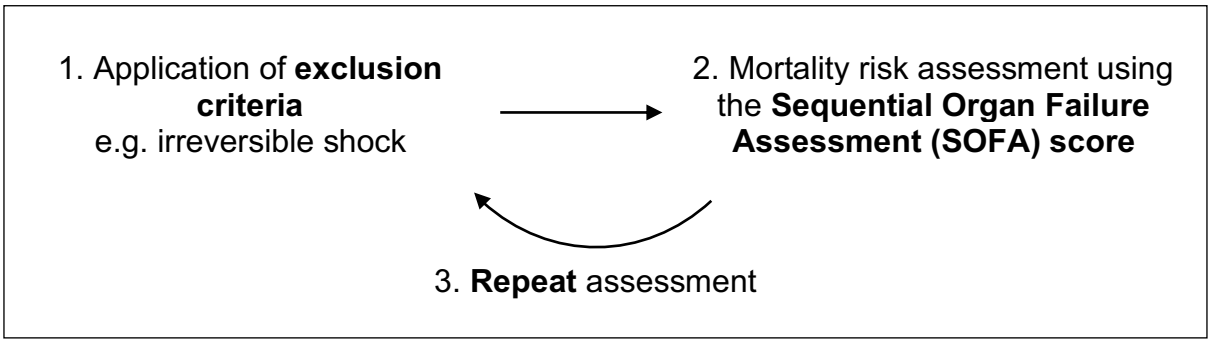
The necessity of a triage committee

1. To buffer clinicians from debilitating and disabling distress as a result from withdrawing ventilators for reasons not related to the welfare of their patients.
2. To maintain caregivers their traditional roles as fiduciary advocates (including to appeal the initial decision of the committee when appropriate), in respect to their patients.
3. To ensure consistent and unbiased decisions across patient groups, including flexible consideration in unique occasions.
4. To remove the responsibility for triage decisions from the bedside clinicians, spreading the burden among all members of the committee.
5. To communicate the decision clearly and accurately to the family, while treating clinicians play the consoling role.

Mechanical ventilation withdrawal team

- Substitutes relevant caregivers to carry out the withdrawing process.
- Should be composed of experts in palliative care and emotional support of patients and families.

Figure 1: Three-step triage.



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CHAPTER 5

The COVID-19 Pandemic: Understanding Duties And Liabilities

Munita Kaur

Lydia Aiseah Ariffin, Mohd Firdaus Abd Aziz, Tan Hui Siu (Reviewers)

"Mr. A was a 36 years old gentleman with no prior medical illness and allergies. He worked as a Grab Driver, and one day while working, he experienced chest discomfort. He started coughing, which led to severe chest pain. He was breathless and could not speak. He could only say, "Saya tak boleh nafas." The customer he was driving took charge and drove him to the nearest hospital. Not knowing anything, the customer just said the Grab Driver was having bouts of cough and suddenly experienced difficulty in breathing. Dr. B worked at the triage of Hospital that morning after 3-night shifts, covering for another friend who was quarantined. Hearing the complaints by the passenger, he wanted to rule out COVID-19. Dr. B alerted the team for that possibility. Mr. A was severely breathless that he could not speak or give any history. While transferring Mr. A to the Respiratory Resuscitation area, Mr. A collapsed. It was nearly 5 minutes before the HCW attended him as they had to put on their full Personal Protection Equipment (PPE). However, Mr. A succumbed to his illness, during the post-mortem, the cause of death was of Myocardial Infarction. COVID-19 was ruled out. Mr. A's family was dissatisfied with the management and accusing the hospital of negligence on the account that they had misdiagnosed Mr. A, and the treatments were delayed and suboptimal because of that shortfall."

Key Points:

- COVID-19 raises many legal and ethical issues
- Existing ethical guidelines are ill-equipped to guide our healthcare professionals
- The lack of pandemic based guidelines would result in confused duties and risk, legal exposure
- Existing legal principles remain untested in the era of COVID-19. How the courts would respond to decisions taken by healthcare professionals during this pandemic is not clear.
- The value of ethical guidance cannot be unstated. There is a duty to be transparent.
- Our healthcare professionals need not only the ethical and moral guidance during this time but also a guidance on best practices to avoid liability.

The COVID-19 pandemic has created a public health emergency forcing healthcare professionals to work under unchartered circumstances. In countries where the pandemic has been hit hardest, healthcare professionals have been forced to make difficult choices on whom to treat and when to stop treatment. The pandemic has also placed unprecedented stress on healthcare services and workers around the globe. Healthcare professionals are being asked to volunteer their services, called out of

retirement and final year medical and nursing students are graduating early to help on the frontlines. Underlying these precarious calls of duty is an uncertainty on the scope of duty owed by healthcare professionals and concern over their potential exposure to legal liability. As healthcare professionals move from individual care to caring for society at large, existing ethical guidelines regulating their conduct appear ill-suited to the task ahead.

The current Ministry of Heath guidelines does not focus on the ethical aspects of clinical practice and decision making. This phenomenon is concerning as it risks decisions made in these challenging settings to be questioned and disputed in the court of law. Theoretically, a healthcare professional risks both civil and potentially criminal liability, however, realistically those who provide the best care possible following recommended guidelines and strategies are unlikely to be faulted. Hence, the need for ethical guidance is vital not only to guide proper clinical decision making but also to ensure our healthcare professionals have the best defence available should their decisions be called into question.

Current Ethical Guidelines Are Simply Inadequate

The Ministry of Heath has issued a comprehensive list of clinical and administrative COVID-19 guidelines[1], including clinical guidelines on PPE and the management of mental and psychological well-being of healthcare professionals. As the Ministry continues to add to the list of guidelines, missing from them is guidelines relating to the ethical aspect of clinical practice and decision making during a pandemic. Professional bodies have also largely remained silent on this front.[1]

This is in stark contrast with the International response. The General Medical Council (GMC) of the United Kingdom (UK) has for example, developed an FAQ page and resource links from the various medical colleges addressing the many ethical issues relating to COVID-19.[2] The UK's Royal College of Physicians, supported by a dozen other heath organisations, has further released an 8-page general ethical guide[3] which includes general advice on ethical issues[2] and links to other valuable ethical resources and advice from the government and public health department.

The UK is not alone, America, Australia, and many European countries have rapidly developed extensive ethical guidelines in response to the pandemic. Admittedly, the COVID-19 situation in Malaysia is not dire; and let us hope our healthcare professionals and Malaysians never face the full wrath of COVID-19; this however should not be a reason to ignore the need for homegrown ethical guidelines which are reflective of our social and moral fabric.

Existing Malaysian Medical Council guidelines are simply ill-suited to the situations we find ourselves in. Malaysia's 'Good Medical Practice' "Privacy and Confidentiality' and 'Informed Consent' guidelines simply do not address the novel issues this pandemic raises. How are concerns on patient autonomy, privacy, confidentiality, and family preferences to be managed in the current environment is not clear. Guidelines such

[1] At the time of writing only The Malaysian Medical Council has issued guidelines on Telemedicine
[2]Such as 'Caring for COVID-19 vs Non-COVID-19 patients', 'Making difficult decisions', Support for difficult decision', 'PPE for frontline staff' among many others.

as 'Managed Care Practice', 'Medical Records' 'Medical Practice for Doctors beyond the Age of 70' need to be reviewed form the lenses of COVID-19. Our healthcare professionals are yet to perhaps face the more difficult ethical questions raised by the pandemic, but this is not to suggest that they have not had to grapple with ethical issues. How to manage COVID-19 patients beyond their skills and competencies, patient's dishonesty, and concerns over inadequate documentation posed by the need to discard contaminated ICU charts, are just some questions our healthcare professionals already have.

Transparent, acceptable and agreed ethical guidelines need to be adopted not only to help our healthcare professionals navigate the many difficult decisions they may have to make, but also to persuade the courts, should the need arise, that our healthcare professionals acted appropriately. Hospitals need to prepare and those in charge need to provide those on the frontlines with guidance. Where guidance is provided and a healthcare professional acts accordingly, he must not be faulted. Failure to guide, on the other hand, may result in the liability of healthcare providers and so would carelessly prepared guidelines.

Some Examples Of Liability Concerns

Triage

The current legal principles remain untested and how the courts would respond to decision taken by healthcare professionals remains to be seen. Although difficult triage decisions have yet to confront our frontlines and the COVID-19 situation appears contained to date, it could change rapidly as evident from Singapore's experience. Should the time come, and our healthcare professionals are forced to make difficult triage decisions on who receives treatment and who does not, they will need moral and ethical guidance. Difficult triage decisions would ultimately lead to some patients being left without treatment or 'appropriate treatment'. Such triage decisions are not routine as elucidated by an NHS doctor: '*Every day, doctors wrestle with decisions about what is right for the patient in front of them. But when resource-based triage occurs, the decisions become about what is in the "greater good" and "doing the best for most*"'.[4]

Current guidelines are of little use in such a situation. The lack of guidance and decision taken on an ad-hoc basis, shrouded in secrecy and without any clear protocols are bound to be challenged exposing both healthcare professionals and the institutions they operate within to potential liability. It is important for difficult decisions on triage therefore to be made in a transparent manner. How they are to be made, what are they to be based on and how they may be justified must to be made known to the public at large and a consensus obtained. The Royal College of Physicians state that "guidance should be accountable, inclusive, transparent, reasonable and responsive".[5]

Daniel Sokol, a barrister and medical ethicist argues that although no protocol published or adopted would please everyone, and would no doubt be vulnerable to judicial review and legal challenge, 'it is preferable to hear those challenges now, when changes can be made at little cost, than later when lives may be lost unjustly.'[6]

In cases where resources are not an issue, the traditional dimensions of duty of care would apply to both triage and treatment decisions. The issue then turns to the standard of care. The prevailing standard of care in Malaysia with regards to diagnosis and treatment is the English common law '*Bolam* test'[7] as qualified by '*Bolitho*'[8, 9]

The *Bolam* test questions decisions taken by healthcare professionals with reference to whether those decisions are supported by a reasonable, respectable, and responsible school of thought within the profession. In *Bolitho*, such a school of thought was held to be one whose views were capable of logical analysis. Logical analysis means decisions taken by healthcare professionals must be evidence based. A healthcare professional who satisfies these requirements is not in breach of duty.

In terms of a healthcare professional's duty to disclose risk associated with treatment, informed consent must be obtained.[10] Hence any failure to warn patients of their COVID-19 diagnosis, prognosis and/or treatment options could attract liability.

How these tests would work in a pandemic however remains untested. Stressed, overworked, and fatigued healthcare professionals who may have to make quick decisions are not immune from carelessness. Although, how the actions they take will be judged remains to be seen, the following is clear: breach of duty is to be determined without the benefit of hindsight[11]; and 'error of judgment' may not be negligence[12].

Liability concerns for healthcare professionals working voluntarily and beyond their usual disciplinary boundaries and specialities are real. Missing key symptoms and poor referral decisions could attract liability. Once again, the legal position remains untested and the following ought to be noted: junior doctors must come up to the standards of reasonably competent doctors[13]; a healthcare professional would be judged against the minimum acceptable standards within his/her profession; and that context and circumstances may be deemed relevant in establishing the appropriate standard of care[14].

Further, as both the medical and scientific knowledge on Covid-19 is still developing, it remains to be seen whether the courts would, in the event of any uncertainty on issues of causation, choose to lean in favour of no liability or modify the test on causation to establish liability.

'Considering past cases and the law's approach, the importance of clinical guidelines, protocols, staff training, competence assessment, and induction assumes a vital significance, and all steps need to be fully documented. Documentation of steps taken, clinical reasoning and deliberation in all these matters will prove crucial in defending any cases brought.'[15, 3]

[3] *Please refer to the Chapter on the Ethical Dimensions on the Standard of Care*

Conflicting duties

Healthcare professionals owe a general duty of beneficence to patients and hence a general obligation to be on the frontlines during a pandemic. However, they also have other competing duties namely a duty to protect themselves from undue risk of harm, a duty to their family and a duty to their colleagues whose workload would be impacted should they be rendered unfit to serve.[16] Hence the questions, 'what is an acceptable level of risk to the healthcare professional? When does the risk cease to be reasonable, who should decide'[17] and whether there should be liability should a healthcare professional decide not to treat?

Professional organisations around the world appear to suggest that a doctor must not refuse to treat patients simply on grounds of personal risk.[18] This view has met with some resistance from ethicist. Sokol argues that a physician's duty is not limitless and needs to be balanced against other competing duties[4] whilst bioethics Udo Schuklenk[5] argues that healthcare professionals are under no ethical obligation to treat COVID-19 patients[19] considering the PPE crisis[6].

Given the uncertainty immediate guidelines must be developed to ensure healthcare professional have proper guidance on the issue.

The Value Of Ethical Guidelines During A Pandemic

Clinical ethics in a pandemic span across the nuances of social justice, human rights, social determinants to health, patient-physician/surrogate-physician relationship, shared decision making, expanded dimensions of autonomy, paediatric bioethics, patient-physician relationship, end to life ethics and much more.[7] Hence, healthcare decisions cannot be made in a scientific vacuum devoid of a moral dimension as "every discourse about health care has not only a scientific but also a moral dimension, [pandemic influenza] plans also presuppose certain ethical values, principles, norms, interests and preferences"[20].

Pandemic reality is such that healthcare professionals will often be asked to make difficult decision on who lives, when to treat and when to not, how much to personally risk and when to hold back. They should not have to navigate these moral dilemmas without guidance. Ethical guidelines provide the much-needed moral validation for the difficult decision they are being called to make.

Ethics is also important to the debate on issues such as the level of harm the public is prepared to accept, how the burdens of negative outcomes should be distributed across the population, whether or not more resources should be invested in stockpiling medications and essential equipment, and accountability transparency and trust.[21]

[4]As quoted in Lives on the line? Ethics and practicalities of duty of care in pandemics and disasters supra n.12

[5]Professor of Philosophy and Ontario Research Chair in Bioethics

[6]Which she attributes to budget cuts and a lack of planning by the government.

[7]Please refer to Section 3 on Clinical Ethics Dimensions for further chapters related to these ethical dimensions and the challenges in clinical practice and decision making.

The cost of not addressing ethical concerns is dire. Loss of public trust, low morale among hospital staff, confusion about roles and responsibilities, stigmatisation of vulnerable communities, forcing healthcare professionals to make things on the go and misinformation are among the many consequence of a failure to engage ethics.

As Sokol argues 'Medical ethics is a practical discipline.' It does not simply exist for the purpose of asking interesting questions, 'It must provide concrete advice for clinicians on the forefront.'[22] It is time Malaysia to provides its healthcare professionals with ethical guidance.

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CHAPTER 6

Privacy And Confidentiality During A Public Health Crisis

Hazdalila Yais Haji Razali, Aimi Nadia Mohd Yusof, Hafizah Zainal Abidin

"Dr. Z was a junior house officer working in Hospital K. On the way to his ward, he witnessed a patient having a seizure in front of the emergency department. Feeling excited about the event, which was the first time for him, he recorded the whole event exposing the patient's face with running commentary, listing out the symptoms of a seizure, including the incontinence. He then posted it on his Instagram as a doctor disseminating information and advice. He shared it with his friends and family, intending to increase their awareness of seizure. Unfortunately, Dr. Z's friend, Mr. B, viralled the post to ask viewers to pray for Mr.M's recovery. Within 6 hours, the news spread across the country.

Key Points:

- Privacy and confidentiality are essential in enhancing trust between healthcare workers and patients, which include protecting their personal information and private matters.
- Patients data should be circulated using appropriate medium by respective practitioners only with related clinical or public health teams.
- Social media usage among healthcare workers are increasing both in work and personal matters. Measures need to be taken to ensure the security of patient's related data.
- In unforeseen circumstances, of which privacy had been breached, steps must be taken to minimise further damage.
- There should be measures to manage the psychosocial impact from a breach of privacy and confidentiality.

A. Introduction

The COVID-19 pandemic has seen a shift from patient-centred care to patient care that is guided by public health interests. As a result of this, some elements pertaining to the principle of privacy and confidentiality may be jeopardized. This is because the privacy interests of affected individuals, the need for surveillance for public health purposes, and the opportunities for research to ensure scientific progress have to be balanced with that of patient care.

Privacy: is the right of an individual to control how his/her personal health information is collected, used, and/or disclosed.
Confidentiality: is the duty to ensure information is kept undisclosed only to the extent possible.

Privacy and confidentiality require that the personal information of an individual be protected. Maintaining confidentiality **enhances trust in a relationship** such as that between a doctor and a patient. It encourages patients to be truthful in their communication with their doctors.

It is, however, essential to note that the duty to confidentiality is not absolute, and that occurrences such as a pandemic may allow the ethical and/or legal justification for a breach in confidentiality. Clinicians are required to disclose pertinent patient information to other healthcare workers (HCW) involved in the care of that particular patient. They are required to notify public health authorities in accordance with provisions in the Prevention and Control of Infectious Diseases Act 1988.

Thus, sharing of specific patient information with other individuals unrelated to the care of the patient, for example, would **be unlawful and unethical.**

Case scenario:

Mr. X, who has recently returned from Italy, develops upper respiratory tract infections symptoms. Since his return, he has been observing a self-quarantine diligently and presented to the nearest designated COVID-19 screening centre for investigation and eventual management when he tested positive for COVID-19. The hospital and the public health authorities had the privilege to obtain information shared by Mr. X.

However, can the public health authorities disclose the fact that Mr. X had contracted the illness to his employer and colleagues? Should his neighbours know about this even if Mr. X did not have any contact with them since his arrival back in Malaysia? Should the information that Mr. X was the 100th COVID-19 patient in Malaysia (Patient 100) and his travel history be made public? These questions are important to identify the sort of information that can justify a breach of privacy and confidentiality of the basis of public interest.

Unfortunately, Mr. X's information was leaked on social media, and this led to him receiving criticisms by internet users for travelling to Italy. He also faced discrimination after he was cleared from the virus and discharged. He had to resort to wearing a face mask to prevent himself from being publicly recognised. The cyberbullying and discrimination have caused him significant distress and led to him feeling depressed about the fact that he contracted the illness.

B. Limits to Sharing Details and Identity of Cases

Registered medical practitioners in Malaysia are bound to the ethical guidelines on Confidentiality published by the Malaysia Medical Council (MMC) in 2011. It provides for 4 conditions when a medical practitioner can disclose personal information:

- when disclosure is required by the law,
- when disclosure is consented by the patient either implicitly or expressed,
- when disclosure is in the patient's interest and
- when disclosure is justified in the public interest.

According to the 2019 revised Code of Professional Conduct (which is currently not yet in force), only relevant information should be disclosed for specific reasons when disclosures are justified. Also, when the release of confidential information is required, the patient must be informed of such disclosure.

"An anonymous survey conducted by Zoya, et al. (2017) involving 366 healthcare workers in Texas revealed that 97% of them owned an electronic device, and that 87.9% used social media. Although the usage of social media among physicians and nurses were identical (88% for each group), only 1.7% reported the use of social media for work-related purposes and 40.8% of them were reportedly unaware of their institutional policy on social media use. Furthermore, the survey found that even though almost every HCW used electronic devices that could allow the utilization of social media or other applications that permits information sharing and for education purposes, only a few of them use social media appropriately and legally. This means that there were many opportunities where a breach of confidentiality could happen, such as when someone unknowingly exposes information regarding a patient when casually posting a picture of a day at work. There have also been cases reported where information circulated as privileged communication[8] was unintentionally leaked (such as contact details of Human Immunodeficiency Virus (HIV) patients to unwanted third parties)."

In Malaysia, Personal Data Protection Act which was in force in 2010, is an act whereby to regulate the privacy of data that is shared by individuals. In section 39, disclosure of data are permissible if consent is obtained, in prevention of crime or required by law. As for sensitive data for medical purposes in section 40, disclosure can be considered when it is undertaken by HCW or persons who owes duty of confidentiality.

The question is whether the COVID-19 pandemic has required a significant change to the practice of confidentiality among HCW or the same practices of confidentiality that are practiced before the pandemic are still applicable.

In an event where HCWs are in doubt of their action, consultation and discussion with a superior can be done. In circumstances where a decision is still unable to obtained, consulting the clinical ethics committee, medical advisory committee, hospital legal advisors or medical division of MOH may need to be done. Hence, it is important for HCWs to know where and whom to consult when they have any uncertainty.

[8] Privileged Communication is an interaction between two parties in which the law recognizes a private, protected relationship. Whatever is communicated between the parties remains confidential, and the law cannot force their disclosure. The established privileged communications are those between wife and husband, clergy and communicant, psychotherapist and patient, physician and patient, and attorney and client.

HCWs need to be aware of the actions that can be taken against those who leak information or breach the confidentiality and privacy of a patient means without proper justification.

Disciplinary action can be taken via the Malaysian Medical Council and other Allied Health Professional Bodies such as Nursing Board or the Malaysian Dental Council. Besides, civil proceedings can be initiated against them by their patients. Those who are working in the government sector may have actions against them through warning letters, demotion, or even termination of work.

C. Protecting The Confidentiality and Privacy of Patient's Medical Information.

Do's

1. The patient's personal details that are collected need to be justified and shall not be further processed in any manner incompatible to that purpose(s).
2. Use anonymized patient information instead of full names or coded information such as patient n = 100, if it is practicable and able to achieve the purpose.
3. Keep disclosures to the minimum necessary. The information obtained should be documented securely in the patient's file and only accessible to personnel with direct care to the patient.
4. The personal data should be accurate and keep up to date and shall not be kept for longer than is necessary.
5. The institution that collects the data should be aware and comply with all relevant local legal requirements. Appropriate technical and institutional measures shall be taken against unauthorized or unlawful access, accidental loss or destruction of medical records.
6. Any healthcare practitioners shall respect and assist patients if they want to be informed on how their information might be used and if they might want to have access to or copies of their health reports and medical records.
7. Practitioners need to practice confidential precautions when sending any confidential materials by electronic mail, facsimile, and mail.

Don't s

1. Do not use identifiable patient information unless absolutely necessary.
2. Do not leave sensitive messages such as diagnosis on answering machines or voice messaging systems.

D. Important Points from Circular from DG of MOH No 10/2016: Guidelines for the Use and Monitoring the Use of Social Media Among Health Care Providers

1. This guideline is published as a guidance for the use and monitoring of the use of Social Media among HCWs during patients' consultations.
2. Social Media in this circular includes any online communication in virtual communities and network including Facebook, WhatsApp, Viber etc.
3. The use of social media is allowed for consultation, referral, and health education of HCWs.
4. All identifiable information shall be excluded from any information transmitted through social media. This includes; patients' information, information of the HCWs and the health facilities involved.
5. All images uploaded and transmitted must obtain written consent from patients except in the situation where a patient could not give consent.
6. The consultation and the media use must be documented in the patients' notes.
7. The exchange of information must not be done in a manner that is accessible by someone who is not connected to the care of patients.
8. All stored information in mobile devices must be deleted after completion of the consultation.
9. Consultation should be initiated by telephone before social media is used.
10. Person in charge or PIC of the health facility shall ensure that all HCW in their facility read and understand the circular and be aware of all the chat group in the facility.
11. HCWs shall be responsible for the authenticity of the information shared and confirm the identification of the receiver.
12. Social media should not be used for consultation among patients and HCWs and between government and private facilities unless with special permission from the PIC.

E. How To Mitigate The Psychosocial Impact Of Breaches In Confidentiality

Certain things that go beyond our control.

The first step in managing breach of confidentiality **is damage control.** If the breach is at an early stage, the retraction of information may be the best initial step. Retraction should be done by deleting any wrongly written information and should be done formally. Assess the degree of damage done and take measures to stop the circulation of the information. Apology towards the victim in an event where confidentially is wrongly done can also be an initial damage control step.

If things get out of hand, psychosocial risk management is crucial, and there is an **ethical need to re-create the trust** between health care practitioners, patients, and

their families. Managing this risk involves a systemic, evidence-based approach and establishment of quality information prior to the designing of the intervention. The risk management action plans need to be evaluated and should include reassessment and adjustment of an intervention. Both healthcare practitioners and patients need to work together to reduce the risk of breach, and both parties should carry out the risk management process. These steps include:

- Thoroughly debrief parties that are directly involved in the incident and assess their understanding of the severity of the issue and insight about the incident.
- Assess the mental and emotional state of those involved.
- Provide counseling or psychological support for those involved and experience distress.
- For those who are in a panic, help them to **S**top and **T**ake a deep breath, **O**bserve the situation, and **P**roceed constructively to think of effective options. (S.T.O.P technique)
- Identify and manage anger by applying S.T.O.M.P Technique (**S**top and count to 10, **T**hink rationally, **O**ptions to have, **M**ove on it and **P**raise as a reward)
- Communicate effectively, elect a representative from affected parties to discuss and work out for a solution to prevent further harm, and control the current situation.

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CHAPTER 7

Ethical Considerations For Utilizing Telemedicine During COVID-19

Muhamad Zaid Muuti, Hazdalila Yais Haji Razali, Kanny Ooi, Mark Tan Kiak Min

> "The delivery of healthcare services, where distance is a critical factor, by all health care professionals using ICT for the exchange of valid information for diagnosis, treatment, and prevention of disease and injuries, research and evaluation, and for the continuing education of healthcare providers, all in the interests of advancing the health of individuals and their communities"
>
> ***WHO on Definition of Telemedicine***

A. What Is Telemedicine?

'Telemedicine' simply means 'healing at a distance' when the patient and the health professional are in different locations. It is also referred to as **'**Online Medical Consultation', 'Remote Medical Consultation' or 'Virtual Medical Clinic'. In this guideline, Telemedicine is defined as; **direct patient to doctor consultation by utilising Information and Communication Technology (ICT) for medical care or advice**.

Recently, the Ministry of Health launched a free COVID-19 Virtual Health Advisory Portal, which allows the public to communicate with a doctor via an online chat, audio or video call ("Free Online Consultation", 2020). The platform allows doctors to obtain the patient's medical history and to advise them based on information provided by the patient. Any **advice given to an individual patient by a registered medical professional,** is considered to be within the scope of telemedicine even if there was no diagnosis made or treatment given.

B. Why Is Telemedicine Important?

In a typical medical consultation, the patient and the doctor are physically present in the same room. However, due to logistical challenges and geographical barriers, some patients may not have access to healthcare services. The World Health Organisation (1997) has proposed using telemedicine to address these barriers. Following the recommendation by the WHO, the Malaysian government have launched a masterplan called the "Telemedicine Blueprint" which aims to transform the healthcare system by harnessing the power of ICT. Additionally, the Telemedicine Act 1997 has also been passed to regulate telemedicine in Malaysia; however, it remains unenforced until today.

With the current COVID-19 pandemic, the interest on telemedicine has been invigorated. Social distancing practice such as those contained in the Movement Control Order enforced by the government has made it more difficult to access to healthcare services. As a result, numerous outpatient appointments have had to be deferred (Ministry of Health, 2020). Telemedicine has the potential to address these challenges.

Moreover, the Malaysian Medical Council (MMC) has also recognised the importance of telemedicine, with the release of an advisory notice on telemedicine practice during COVID-19 pandemic (Malaysian Medical Council, 2020).

C. How Is Telemedicine Delivered In Malaysia?

In general, telemedicine can be delivered through three (3) category of technologies:

i) **Text-based technology**, such as SMS, online chat or email.
ii) **Audio-based technology**, such as phone call or online voice call.
iii) **Video based technology**, such as online video call or Facetime.

There are pros and cons to each category. For example, text-based consultation is possible even when the patient does not have any internet access, but it could be difficult for the doctor to verify the patient's identity.
There are also **online telemedicine platforms** that incorporate all three technologies and **allow doctors to prescribe medication remotely**. These include BookDoc, doxy.me, Doctor On Call, etc.

D. Disadvantages Of Telemedicine?

There are several disadvantages to telemedicine, such as:

i) High risk of medical error

- The inability to perform a complete physical examination is one of the main drawbacks of telemedicine. While obtaining a detailed medical history may be adequate for making a diagnosis in some instances, a physical examination remains a useful way of verifying the patient's symptoms. In a study by Verghese et.al (2015), 63% of the total medical error in a healthcare facility were the result of failing to perform a physical examination. The authors concluded that a physical examination is valuable for reducing the risk of a misdiagnosis.

- Miscommunication during telemedicine may contribute to medical error as well. Miscommunication may occur due to the inability to discern non-verbal cues or simply due to technical glitches such as interrupted signal or low quality of image transmission.

ii) Privacy and security issues

- Online communications are vulnerable to security breach even with the strictest privacy settings. There are numerous local reports on security breaches that cause patient's medical information being accessed by unauthorised third parties (Nazlina, 2015; Habibu, 2019).

- Online identity theft may occur through various methods such as phishing, pharming and spyware that can result in doctor's or patient's account username and password be stolen. This may compromise a patient's privacy.

- Secure servers are required to store records of the teleconsultation such as video recordings, medical notes, etc.

E. What are some ethical considerations for telemedicine?

Here are some ethical considerations relating to the practice of telemedicine

i) The establishment of the doctor- patient relationship

- The therapeutic relationship between doctor and patient is permeated with ethical duties and is based on trust.
- Similar to the practice of in-person consultations, telemedicine requires a doctor-patient relationship to be forged

ii) Duties associated with the doctor-patient relationship

- The ethical duties of a doctor in the practice of telemedicine should remain the same as those related to in-patient care
- This relates to the duty to confidentiality, ensuring the privacy of patient records, respect for autonomy, beneficence etc.
- Registered medical practitioners who practice telemedicine are bound to the same ethical codes issued by the MMC

iii) Rationing of scarce healthcare resources

- Telemedicine consultations can serve as a triage in order to prioritise patients for COVID-19 screening
- Doctors should act judiciously when providing instructions for screening, taking into account information provided by the patient the indication prescribe in the management guidelines
- The use of telemedicine may also reduce the usage of PPE as the consultations are not conducted in-person

iv) Increasing access and improving efficiency

- With telemedicine, quality healthcare can be delivered to patients living in the rural areas.
- The convenience of telemedicine may also benefit the urban population. The traditional healthcare delivery is often plagued with long waiting time and inflexible appointments that may discourage patients from seeking treatment.
- In the United Kingdom, the Royal College of General Practitioners (2013) have suggested that telemedicine is able to reduce unnecessary visit, reduce waiting time and allow patients to be seen more quickly.

v) Minimising the risk medical error in telemedicine

- The main drawback of telemedicine is the high risk of medical errors. However, telemedicine can be safely delivered if patients are carefully selected.

In the circumstance where physical examination is required, medical practitioners should refrain from issuing prescription and advise the patient to seek care in person.

F. Telemedicine For Outpatient Care

In the outpatient setting, telemedicine can be utilised in two (2) situations, namely:

a) Telemedicine where the doctor and patient have previously met in person

In this situation, the patient and the doctor have previously met in person. The doctor has prior knowledge of the patient's condition and has access to the patient's medical records. The purpose of this method of telemedicine are:

i) For follow up and monitoring of previously diagnosed conditions
ii) For reviewing and changing the dose of medicines previously prescribed
iii) For starting new medication for known conditions
iv) For treating known conditions (i.e. through using means such as psychotherapy)
v) For diagnosing and treating new conditions
vi) For medical advice
vii) For remote prescription

b) Telemedicine where the doctor and patient have never met in person

In this situation, the patient and the doctor are meeting/communicating for the very first time. The doctor has no prior knowledge of the patient's condition and does not have access to patient's medical records. The purpose of this method of telemedicine are as follows:

i) For diagnosis of new condition
ii) For medical advice

Remote prescribing is not advised and may constitute a breach of the MMC's Guideline on Good Medical Practice, which mandate a physical examination to be performed before the issuance of a prescription. Therefore, if the patient requires prescription, the patient should be advised to see the doctor in person.

The MMC Advisory on Virtual Consultations (during the COVID-19 pandemic) also states that virtual consultations should only be conducted by doctor with persons who are already their patients, as this can be part of continuation of care of the patient.

It does however qualify that special circumstances do arise where healthcare delivery is affected by pandemics or movement restrictions, and during this limited time, registered medical practitioners who conduct virtual consultations and feel, in good faith, that they are able to make an accurate diagnosis based on the history provided by the patient and limited visual and auditory observation, then appropriate treatment can be initiated.

4.1 Prescribing
4.1.1 A doctor should not issue a prescription without examining the patient, unless the doctor is already familiar with the patient and his illness and his medications through previous consultation.
4.1.2 A doctor must not prescribe medications to a caller who has not yet established a personal doctor-patient contract, merely on listening to a complaint over the telephone or any other electronic device.

Malaysian Medical Council, Good Medical Practice[1], 2019

G. Good Telemedicine Practice

Before starting

a) Determine whether telemedicine is suitable for the patient
- Ensure the patient knows how to operate the device for the consultation
- Ensure patient has access to the internet or communication lines
- Ensure that the equipment/device you use for the telemedicine consultation is secure and fit for purpose.
- If telemedicine is not suitable, the patient should be advised to seek face-to-face medical care.

b) Obtain consent from the patient
- Explain the limitations of telemedicine including the inability to perform a physical examination and the risks of miscommunication.
- Highlight that even with due care, there could still be technical glitches and security breaches that could compromise the patient's privacy and confidentiality.
- Explain that at times, the patient may need to see the doctor in person following the telemedicine.
- Ensure that the consent taking process is documented in the medical record

At the start

a) Verify patient's identity
- It is important to verify a patient's identity to detect online identity theft and prevent fraudulent transactions.
- Safety measures such as keeping the patient's photograph and verifying their name and address are recommended by the National Health Service (2015).

[1] The 2019 version of the MMC's Good Medical Practice has not yet been enforced.

b) Inform the patient of your identity & credentials

- It is the right of the patient to know the details of the doctor.
- Furthermore, It is a requirement by the MMC that each patient is informed of the practitioner's name, MMC registration number and primary place of practice (Malaysian Medical Council, 2020).

- This allows the patient to contact the doctor in person if the need arises.

During the consultation

- Consider whether a physical examination would add critical information. If it is determined that medical care or advice cannot be given safely without a physical examination, a face to face consultation should be arranged.

- In some circumstances, it may be necessary to ask another medical practitioner to conduct a physical examination on your behalf. In those instances, consent from the patient should be obtained before any arrangement is made.

- Transfer of care may also be necessary in some instances. In those cases, adequate information regarding the case should be conveyed to the receiving practitioner or facility. It is also important to provide your contact information should any queries regarding the case arises.

At the end

a) Give patients the opportunity to ask question regarding their conditions
b) Advise patient to seek face-to-face medical care if their symptoms persist or worsen.

At all times

a) Update the patient's medical records
Ensure the patient's medical records are updated after the telemedicine. Details of the consultation including what was discussed, any relevant clinical findings, and any advice given regarding treatments, prescriptions, and follow-up should be documented.
b) Adhere to Good Medical Practice and other guidelines published by the Malaysian Medical Council and the MOH.

H. LIABILITY IN TELEMEDICINE

In countries such as England, New Zealand and Singapore, doctors are expected to deliver the same standard of care through telemedicine as care provided in an in-person consultation (Care Quality Commission, 2017; Medical Council of New Zealand, 2020; Ministry of Health (Singapore), 2018). The same principle applies in Malaysia.

To reduce the possibility of a misdiagnosis, doctors must take a detailed history from the patient. Doctors should decline to prescribe remotely if they lack vital information about the patient. In other words, they should only prescribe a medicine or treatment following an adequate assessment of the patient's condition, and are satisfied that the medicine or treatment is in the patient's best interests.

Before embarking on providing telemedicine services, doctors are advised to check with their indemnity insurance whether telemedicine is covered in their policy.

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CHAPTER 8

Ethical Dimensions Of Standards Of Care During COVID-19

Tan Hui Siu, Erwin Khoo Jiayuan, Azanna Ahmad Kamar

"Danish is a 16-year-old adolescent with Ewing's sarcoma with metastasis to lungs and spine. He is on palliative care. He has been in the ward for the last 3 days for pain management and blood transfusion. Due to COVID-19, the bed strength and staffing of the ward have considerably reduced. The attending physician feels that Danish should be transferred to the nearby district hospital for the continuation of his care. Danish is distressed with the decision."

The ethical issues during scarce resources and crisis standards are challenging because they challenge many of the values clinicians hold, such as providing the best available care to each patient and respect for his/her autonomy and values(1).

During a pandemic, even when resources are adequate, clinicians need to respond to the outbreak crisis management phases of containment, delay, mitigation, and suppression(2). "There is a **tension** between the **patient-centred approach of clinical care** on a normal day and the **public-centred approach of clinical care** during the pandemic crisis. The shift to patient care guided by public health duties creates great tension for clinicians, including clinical ethics consultants(3)."

Hasting Centre*: Ethical Framework for Health Care Institutions Responding to Novel Coronavirus SARS-CoV-2 (COVID-19)(3)

Duties of clinical care: *Focus on individual patient*
maintain fidelity to the patient, relieve suffering, respect the rights and preferences of the patients

Duties of public health: *Focus on community*
promoted public safety, protect community health, fairly allocated limited resources relative to need

**Hasting Centre: the U.S. and world prominent bioethics think-tank*

A 2009 Institute of Medicine (IOM) report outlines seven ethical considerations that are crucial to the "development of ethical crisis standards of care protocols: **fairness, duty to care, duty to steward resources, transparency, proportionality, and accountability**(4)." Applying this ethical framework is not always easy as there are challenging issues that rarely have a single "right" answer(1).

The principle of utility concentrates on maximising benefits and minimising burdens(5), while the principle of equity requires attention to the fair distribution of benefits and burdens(6). "**Health equity** is an ethical concept based on the principle of distributive justice. While an equal distribution of benefits and burdens may be considered fair, it may be fairer to give preference to vulnerable groups. There is no easy solution to

resolve potential tensions between utility and equity, but a balanced consideration between both is crucial(7),"

Please refer to Chapter 4 on the Literature Review of the Ethical Framework on Resource Allocation.

The clinical care for COVID-19 pandemic in Malaysia and abroad also depends on the evolving field experience on the ground and new revelations from virology, immunology, and epidemiology evidence. From asymptomatic transmission to cytokine response syndrome, case reports on the clinical observations and correlated laboratory findings of COVID-19 were critical to guide the public health outbreak containment and clinical management of patients(8).

Medical uncertainties keep clinicians on their toes, anxious, and less confident than in the past. Infectious disease, adult medicine, and intensive care experts struggled to determine what the best therapeutic modalities for COVID-19 were and depended on the field experiences from other countries. In Malaysia, clinicians follow the clinical guidelines and updates on COVID-19 from the Ministry of Health official portal(9).

There are potential changes in clinical care during the pandemic. Medical fraternities, under the leadership of the MOH, work together on clinical consensus, provide regular updates, and communicate effectively with all clinicians on how clinical management should be tailored to the safety and interests of their patients. Off-label drug use(10) and research during the pandemic(11) are required to adequately address the medical gaps and uncertainties related to the new virus, respectively. Table 3 illustrates the potential changes and ethically acceptable standard of care during the COVID-19 pandemic. This is the ethical opinion of a clinician, does not reflect any legal equivalent requirements, and should be read with the rest of the chapter.

Table 3 Potential Changes and Ethically Acceptable Standards of Care during COVID-19 Pandemic

Standards of Care Pre-COVID-19	**Standards of Care during COVID-19 Pandemic**	
	COVID-19 Patients	**Non-COVID-19 Patients**
Evidence-based medicine Expert opinion Level of care Licensed drugs	COVID-19 MOH and international latest clinical guidelines and protocols*(2) Expert opinion Off-labelled Drugs Investigational Drugs**	Evidence-based medicine Acceptable revision of care*** Expert opinion Level of care Licensed drugs

**based on EBM and field experience of local and other countries*

*Please refer to **Chapter 18 on Research Ethics and ***Chapter 9 on Navigating through Challenges in Clinical Practice.*

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CHAPTER 9

Navigating Through Challenges In Clinical Practice During COVID-19

Tan Hui Siu, Azanna Ahmad Kamar, Patrick Tan Seow Koon

A. Overview of Ethics in Clinical Practice

Professional Ethics

Under normal conditions, clinicians are trained to care for individuals, responding to their medical needs by ensuring **beneficence and non-maleficence**, respecting their **autonomy** and preferences, and **maintaining fidelity** or non-abandonment. These values are mainly based on professional ethics or professional code of conduct, as quoted in the "Good Medical Practice" by the Malaysian Medical Council(1).

Clinical Ethics

More than that, though, caring for individuals also includes the **nuances of patient-physician and surrogate-physicians relationships and interactions**. We should consider the values and preferences of patients in a **shared decision-making** model. We need to deliberate on the **voluntariness** of patient autonomy, the **power differences** in a consultation room, the **social determinants** to health and social justice issues, and the **psychological or relational aspects of decision-making** that are related to these factors. We need to consider how to assess for **decisional capacity**, how to respond to an informed refusal, and also to consider the new option of a waiver to decision-making. Lastly, **the cognitive and implicit biases** among clinicians are hardly discussed in clinical practice in Malaysia. These areas are usually covered in the less-mentioned arena(2) (from a Malaysian context) of clinical ethics(3) and its extended domains (Table 5).

Virtue-based Ethics

Also, the attitudes that should govern clinicians should be based on virtue ethics. It is essential that clinicians conduct their practice in accordance with local laws, the professional code of conduct, and also virtue-based ethics(4) (Table 4)

Table 4 Edmund D Pellegrino's Descriptions and Justifications on the Virtues of a Good Physician(5)

Fidelity to trust	It is essential if healing and help are to occur.
Benevolence	The prime precept of medical ethics to act for the good of the patient and avoiding harm.
Intellectual honesty*	Medicine is a powerful instrument for good and harm depending on how medical knowledge and skill are used. Knowing when one does not know and having the humility to admit it and to obtain assistance are virtues crucial to avoiding harm.
Courage	The physician must expose herself to the dangers of contagion, to possibilities of physical harm in emergencies, and to political retribution in regimes that enlist physicians in torture, interrogation of prisoners, deceptions of various kinds, and advocating for patients.
Truthfulness	The patient is owed the knowledge necessary for making informed choices, so he can make plans for his own life when disease disrupts those plans.

**Can also be termed as medical humility or self-effacement*

Table 5 Branches of Bioethics related to Clinical Care with Overlapping Domains or Framework (of which none are adequate or exclusive on its own)

	Professional Ethics	**Clinical Ethics***	**Virtue-Based Ethics**
Framework/ Domains*	• Principlism • Virtues	• Principlism • Casuistry Extended domains: • Narrative Ethics • Feminist Ethics • Microethics	• Virtues of a good physician
Sources	• Malaysian Medical Council – Good Medical Practice 2019(1) • Malaysian Medical Council – Code of Professional Conduct 2019(6)	• Principlism by Beauchamp and Childress(7) • Casuistry or case-based clinical ethics by Albert R Jonsen, Mark Siegler, and William J Winslade(8) • Narrative ethics by Martha Montello(9) • Feminist ethics by Rosemarie Tong(10) • Microethics by Robert D Truog(11)	• Edmund D Pellegrino(4,5) • Aristotle(12)

Comments	This is duty-based ethics and includes the code of conduct. It can be rigid, legally-flavoured, involves contract-minded patient-physician relationship and narrow definitions of ethical principles(4).	More on the nuances of clinical decision-making and relationships	Virtues or attitudes that clinicians should hold. It can lapse into self-righteousness paternalism if not sensitive to nuances and aberrations(4).

**Simple description of these ethical framework/domains:*

1. ***Principlism*****:** Respect for autonomy, beneficence, non-maleficence, social justice(7)
2. ***Casuistry*****:** Case-based method of ethical reasoning by using general principles and paradigms to cases. The Four-Box model (four categories of medical indications, patient preferences, quality of life, contextual features) is a categorical approach used for clinical ethics decision-making(8).
3. ***Narrative ethics*****:** A form of story-based ethical reflection and learning; to locate the answers to the "how" and "why" of a difficult case through a person's identity and value system(9).
4. ***Feminist ethics*****:** A framework that rethinks and reformulates traditional western ethics to focus on the different identities and perspectives – "lenses", especially of gender and oppressed/excluded groups.
5. ***Microethics:*** The ethics of everyday clinical practice(11)

B. Navigating through the Changes in Clinical Practice during COVID-19 Pandemic

The changes in clinical care during the COVID-19 pandemic, which are closely related to the public health impetus, are inevitable. Table 6 offers an overview of the ethically acceptable clinical *alternatives* and approaches that clinicians in Malaysia could consider when navigating through the unpredictable and dynamic changes during COVID-19. These suggestions are by no means exhaustive or prescriptive, and open to feedback and revision. This section is also to be read together with the next section on "End-of-Life Decision-Making".

Table 6 Proposed Ethically Acceptable Clinical Care Alternatives and Approaches during COVID-19

Conditions of the Patients	COVID Status	Potential Changes in Clinical Care	Ethically Acceptable Clinical Care Alternatives and Approaches
Well	Positive Suspect	• Better access to care	None

Well with acute illness	Negative	• Poorer access, delay or suboptimal care	Clear information for navigation of care with alternative access through telemedicine.
With co-morbids	Positive	• Better access to care	None
	Suspect	• Delayed or suboptimal care** to co-morbids needs while waiting for results	1) Revision of clinical care/monitoring/follow-up ("step-down" care) is ethically justified with the condition that clinical experts of the field or the senior members of the team are consulted; or multidisciplinary team (MDT) consensus and communication have been made. Strategies to mitigate the negative impact of a revision of care towards the patient's health and life must be in place. 2) Some strategies include telemedicine, medicines postal services, drive-through testing, COVID-19 risk stratification, or modification to medical equipment or physical space to improve safety. 3) These strategies must address: - Respect for persons, his/her values and right to information. - The right crisis management - The latest evidence-based medicine. - Availability of services and competency of healthcare providers - Anticipatory/contingency plans - Regular re-evaluation. 4) These strategies must be communicated clearly to teams, patients, and their families. 5) Ethics consultation can be utilised if available and time permits for complex cases or policymaking indications.
	Negative	• Delayed or suboptimal care** to co-morbids needs as less access to follow-ups or speciality care	
Chronic terminally ill*	Positive	• Unwarranted interventions (may be against personal	1) Revision of care/monitoring/follow-up is ethically justified with the condition that and senior members of the team are consulted or through multidisciplinary team

		wish) that are meant to isolate and treat for COVID-19 ("step-up" care) • Delayed or suboptimal palliative care due to isolation rules	(MDT) consensus. Strategies to mitigate the negative impact of a revision of care ("step-up" or "step-down" care) towards the patient's well-being, values, and wishes must be in place, and palliative/ compassionate care steps are considered. 2) There is a need to honour the needs and wishes of the terminally ill, through advance care planning (ACP) or advanced directives (made earlier) or informed refusal to life-sustaining treatment. 3) Alternative access through telemedicine could be adopted but lack the personal connection for terminally ill patients. 4) Ethics consultation can be utilised if available and time permits for complex cases or policymaking indications.
	Suspect	• Unwarranted interventions (may be against personal wishes) that are meant to isolate for COVID-19 while waiting for results • Delayed or suboptimal palliative care due to isolation and quarantine rules.	
	Negative	• Poorer access, delay or suboptimal palliative care	1) Clear information on the navigation of care. 2) Alternative access through telemedicine could be adopted but lack the personal connection with the terminally ill.

*Terminally ill and immobile patients with conditions such as Stage 4 cancer or end-stage COAD, might not be fit to travel to clinics or hospitals for testing. Thus, they might have been missed and not diagnosed as COVID-19.

**Delayed or suboptimal care may be related to 1) public health measures by the need to institute PPE, isolation, and quarantine procedures to ensure the safety of patients, healthcare workers, and the community; 2) decanting or mobilization of services to secondary care centres.

Please refer to Chapter 15 on Communication, Chapter 16 on Redefining Compassionate Care, and Chapter 14 on Palliative Care.

C. End-of-Life Decisions

The Arguments

"Should science be given a fair chance to prove if humans will get a better hand of this battle? A short but ferocious battle." (HS)

Versus

"It may be more difficult to achieve thinking about palliative care from the outset (for COVID-19 patients with prior severe co-morbids or terminally ill patients), but if it is the Right thing to do for that patient, we have to endeavour to serve justice and explain it (in the documentation) if we can't." (PT)

The Middle Path

Given the rapid progression, possible acute reversible condition, and good short term survival (for Stage 3 or 4 COVID-19), it is clinical and ethically justified that patients with co-morbids may receive treatment and intensive care at the start. In fact, timely intervention is needed, given their pre-existing co-morbids. However, *after a period of time or a "time-based trial",* clinical judgement must be made on the response/futility to treatment and to re-consider the benefits of therapy or life-saving measures for those with previous severe co-morbids or terminally ill patients.

In a non-pandemic situation or when resources and time are available, end-of-life decisions need to be made with patients if they have the capacity for an informed decision (able to make a Choice, Understands, Rational, and Appreciates); or through a multidisciplinary team (MDT) discussion and family conference if the patient is incapacitated. Decisions are based on the patient's previous wishes through a substituted judgement from the family, or best interests principle based on the prognosis and benefits/harms of the therapy if a substituted judgment is unavailable. An ethics consultation or mediation could be sought if there are unresolved conflicts or dilemmas. Please refer to page 67-73 of Malaysian ICU Management Protocols 2019 on Withholding and Withdrawing Life-Sustaining Treatment(13).

In a pandemic situation when resources scarcity have reached a critical stage, the time and opportunities to deliberate on the decision to withdraw care or to revise the goals of care through an informed decision by the patient, team consensus, and family conference (or even an ethics consultation) may not be present. Thus, ethically, it is acceptable to consider a different flow of decision-making, which is safe, transparent, and just.

Please refer to Chapter 12 on Triaging Protocol for ICU Admissions/Beds/Ventilators During Resource Crisis.

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CHAPTER 10

Adaptations To Shared Decision-Making And Relationships

Tan Hui Siu, Azanna Ahmad Kamar, Tan Ru Wei

A. Background on Shared Decision-Making

In shared decision making (SDM), both parties share information: "the clinician offers options and describes their risks and benefits, and the patient expresses his or her preferences and values"; both parties discuss, negotiate and agree on a decision(1,2). SDM activities in Malaysia began around 2010 and a few studies have expressed how patients in Malaysia preferred an autonomous role in decision-making as opposed to paternalistic physician decision-making(3,4).

SDM builds trust, allows self-determination and the right to information, while allowing some physician authority. The "expert medical" doctor, apart from listing out all the options, will also need to point out her recommendations and play an active role to facilitate patient understanding, sometimes through decisional aids.

This is in contrast to the absolute patient autonomy model where the list of options is shared and minimal recommendations are made, and the responsibility of decision-making falls solely on the presumably autonomous patient.

SDM must be seen as a continuum(2,5) -- different forms in different situations.

- **Clear-cut "effective" decisions:** "For some decisions, there is *one clear superior path*, and patient preferences play little role – bacterial meningitis needing antibiotics(2)." This may also fall under what we called a "standard of care."
- **Not so clear-cut:** "For some decisions in which *no intervention meets this high superior bar,* patients need to be involved in determining the management strategy most consistent with their preferences and values(2)." When there are more than one reasonable path forward exist, including the option of doing nothing, various combinations of therapeutic effects and adverse effects are possible.
- **High impact decisions:** For some decisions that include major surgery, invasive procedures, or medication that **have significant consequences** to a patient's health, life, or values, with lasting implications, patient involvement in decision-making is also crucial(5).

The author believes that the elements of patient autonomy and patient-physician relationship in SDM comes with **multifaceted complexities** and must be viewed in-depth and breadth as well.

- The **broader dimensions of patient autonomy** such as decisional capacities, voluntariness, self-trust, value system, relational aspects, social determinants.
- The **nuances of patient-physician relationship** in terms of power differences, trust and self-trust, and duration of the relationship.

Figure 2 SDM as a Continuum

In paediatrics or neonates, the prognosis of survival, quality of life, and long term neurodevelopmental outcome affect how SDM is conducted based on the best interest principle of the child, and between the physician and the parents(6).

- By the usual rule, the less certain of the prognosis or clarity of a superior path, the more that decision-making may be left to parental authority.
- In a less critical case, parents could make some of the lighter decisions based in the "zone of parental discretion."
- A few have advocated for "shared deniability" over "shared accountability" in end-of-life decision-making, in which the burden of making a decision is too overwhelming for families(7).

B. Background on Surrogate-Physician Relationship

"The surrogate decision-maker cannot be just a passive spokesperson for the patient but is also an active agent who develops a complex relationship with the physician."

In the paper "Physician-Surrogate Relationship," Alexia M Torke et al. outlines the key issues affecting this relationship, including time pressure, lack of continuity, a focus on technology, confusion on decision-making roles, surrogate's experiences, values, and emotional stress, and the conflicts among multiple surrogates and multidisciplinary teams. They provide some guidance (Table 7) that we could utilise on a normal day, and also during the pandemic, in dealing with similar issues(8).

Table 7: Alexia M Torke Guide for Surrogate-Physicians Relationship

Key Points	Tasks
Build a relationship early	Initiate contact early and know the patient as a person Focus on common goals first
Recognise emotions and values	Assess and acknowledge the surrogate Use a multidisciplinary approach
Build consensus	Identify points of agreement Negotiate points of conflict

C. Changes in Shared Decision-Making and Relationships During COVID-19 Pandemic and Compensatory Measures

1. Changes in the patient-physician relationship

SDM builds around sharing a common collaborative understanding of scientific and clinical recommendations, and are therefore, an ethically ideal model to adopt when recommendations are new or vague. However, given public health imperatives during a pandemic with strict infection control rules and containment measures, there will be less emphasis on **patient autonomy and shared decision-making** for those suspected or diagnosed to have COVID-19. More so, it may be a criminal offence under the Prevention and Control of Infectious Diseases Act 1988 (Act 342) if patient refuses to be screened, isolated or treated. Nevertheless, this **"moderate patronising" or "conscientious patronising"** practice by the public health officers and clinicians are ethically justified(9) for the safety of both the COVID-19 patients and the public. During an emergency such as intubation or resuscitation, informed consent could be waived as well. An exception may be ethically considered in the presence of an advanced care planning of terminally ill patients, of which an informed refusal may need to be honoured as they face unwarranted or non-beneficial interventions being COVID-19 patients or suspects.

Please refer to Chapter 9 on Navigating through Challenges in Clinical Practice.

In wielding more authority during the COVID-19 pandemic, **clinicians have more responsibility to ensure that they make sound clinical judgments based on the latest evidence and highest level of competency and skills.** They need to keep patients informed and also to maintain privacy and confidentiality.

Please refer to Chapter 15 on Communications and Chapter 6 on Privacy and Confidentiality.

2. Changes in the surrogates-physician relationship

The wishes of family members of COVID-19 patients may not be met given the public health imperatives to control the risk of transmission to all levels of society. These wishes include the rights to visitation, family presence, change of healthcare facilities, and the timing of intervention. Surrogate decision-making by family members on behalf of incapacitated COVID-19 patients may also be reduced to short family briefings or informed assent given the time pressure, limited workforce, and lack of meeting opportunities.

For a compromised shared decision-making and relationships during a pandemic, compensated measures are needed help retain trust, foster mutual understanding, and maintain good relationships (Table 8).

Please refer to Chapter 16 on Redefining Compassionate Care and Chapter 15 on Communications.

Table 8 Recommended Compensatory Measures to Counter the Impact to Patient Autonomy and SDM During the COVID-19 Pandemic

	Compensatory measures
Reduced patient autonomy and shared decision-making	• Keep patient well-informed of her condition, progress, and management plans • Have open and effective communications • Make sound clinical judgments based on the latest evidence with the highest level of competency and skills • Maintain privacy and confidentiality if possible • Consider honouring informed refusal and advanced care planning
Reduced surrogates decision-making	• Keep the surrogates informed of the patient's condition, progress, and management plans according to workforce availability • Have open and effective communication on the goals of care • Acknowledge and respect surrogates emotions and values • Align expectations and emotions early

3. Other Changes

SDM may be required in seemingly mundane decisions, such as the need to breastfeed or to hold or kiss a new born. Taking breastfeeding as an example, the debate and decisions surrounding breastfeeding instructions for the control of this pandemic differ between countries and even within provinces(10-13). At this moment there are still uncertainties of how COVID-19 is transmitted to a newborn. We can deduce that newborns tested positive for Covid-19 were infected horizontally. There is a potential benefit of augmenting the baby's immune response through breastmilk. Therefore, in several informed and shared decision models, expressing breast milk in a hygienic manner followed by feeding of the expressed breast milk to her infant isolated from the mother has been advised for COVID-19 positive mothers who are keen to continue breastfeeding(12). A recommendation to continue to allow a mother to visit provided that she wears a mask has also been advocated(12,13). Parents should be informed of the risks and benefits and institutional and clinical guidelines need to be developed and revised accordingly to the latest evidence.

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CHAPTER 11

The Role Of Institutional Ethics Services

Mohd Firdaus Abd Aziz, Mark Tan Kiak Min

During a pandemic outbreak, healthcare providers (HCPs) will find themselves in an unimaginable situation. They will need to provide care and comfort for patients and their family members whilst keeping in mind their own safety and other duties. Such a stressful situation can cause distress among HCPs. This repercussion can be further compounded if they need to carry out triage protocols due to limited lifesaving resources, or when they feel that certain actions they had to take violate their own moral conscience, or are uncertain of any potential legal liability. It is, therefore, crucial for HCPs to be given clear guidance and moral support in carrying out their challenging duty as front liners in this unprecedented situation.

HCPs may be familiar with the principle of utilitarianism, which simply means they should maximise the number of lives that they could save. However, not many of them have encountered a real-life scenario where they have to make difficult decisions. This is especially the case among more junior staff. HCPs are not trained to deal with patients in situation where they need to ration and allocate lifesaving resources (Senior, J. 2020) Most of them would have a moral distance between academic discourse on medical ethics that they would have experienced in the classroom and in a real clinical setting. During a pandemic, it is likely that they would find themselves in this difficult situation routinely and without knowing what would be the appropriate decision to make, ethically and also legally. Such a situation could cause them moral distress. In order to overcome this, it will be beneficial and handy for hospitals to provide institutional ethics services to facilitate HCPs in their decision making. The following paragraphs explain the role of institutional ethics services and the nature of its operation.

Institutional Ethics Services

- Institutional ethics services facilitate HCPs, patients, and family members to reflect on choices and make informed decisions, with reference to the rights and preferences of patients and the duties of professionals to avoid harm, benefit patients, and act fairly while maintaining professional integrity (Hastings, 2020).
- These services can take the following forms:
    - Clinical ethics consultation services
    - Clinical ethics consultants
    - Clinical ethics committees
- Public health emergencies such as the COVID-19 pandemic require governments, public health officials, physicians and the public to think about how the doctor-patient relationship may change (Lo, 2013).
- An ethically sound framework needs to balance between patient-centred duty of care (which is the focus of clinical ethics under normal circumstances) with public-focused duties (which is the focus of public health ethics) such as ensuring equality of care among patients, and equity in distribution of risks and benefits in society must be considered (Hastings, 2020).

- Governments may institute mandatory interventions such as surveillance, testing, quarantine, isolation, movement control measures, and these may not be in the best interests of individual persons.
- HCPs have a new primary obligation - to act for the common good. They need to consider how a decision for one patient may impact on the spread of an epidemic, on public trust, and on perceptions of fairness.
- In addition, decisions may need to be made within a limited period of time, with limited opportunity to deliberate about a particular case.
- As a result, significant tension and distress can arise among clinicians in carrying out their duty to provide the best for a patient's clinical care while considering whether or not their action would have implications on their duty to protect the public health and also the duty to treat different groups equitably.

Differences in ethical issues during public health emergencies

- The focus of medical service would be on population outcomes
- Individual liberty and autonomy may be overridden
- Physicians would need to adjust their role
- Decision making may be based on weaker evidence due to limited time and resources

Issues that may require clinical ethics deliberation

- Requests by patients for non-recommended interventions
- Refusal by patient of public health interventions
- Determining acceptable crisis standards of care
- Refusal to care for contagious patients
- Allocation of resources such as:
    - Personal Protective Equipment (PPE)
    - Test kits
    - ICU bed and ventilators

Role of Institutional Ethics Services in a Pandemic (Warren, 2020)

- The role of ethicists in providing support when clinical ethics questions arise is best provided in anticipation and preparation rather than when the ethical dilemma has arisen.
- In general, HCPs should follow public health guidelines for the allocation of scarce resources or triage protocols.
- However, there should be procedural due process made available for appeals, and this is an area where ethicists can also play their part in.

Before

- Help to minimize the number of difficult choices HCPs need to make by addressing issues of resource allocation.
- Ensure that the decisions on triaging and other relevant protocols are ethically sound.
- Articulate relevant procedural and substantive values and embed these into response plans.
- Build ethics capacity and develop tools and frameworks that will help health care providers live with the decisions.
- Convey how values have been translated into guidance.

- Support HCPs as well as members of the public by identifying the relevant values and principles that will guide responses.
- Explain shifts in how various values are balanced against each other, with increased emphasis on values such as solidarity, the precautionary principle, reciprocity, and least restrictive means.
- Facilitate considered reflection on ethical values and contextual information.

<u>During</u>

- Provide consultation and support in deliberating on ethical issues that arise in the management of cases that are especially challenging, and by doing so:
    - Clarify values and facilitate the use of relevant ethical decision-making frameworks.
    - Provide validation that the decisions facing health care providers are ethically fraught and that no choice will feel like it's deeply "right."
    - Acknowledge that there is no single "right" option and that a range of responses could be ethically defensible.
    - Confirm that appropriate procedural and substantive values are reflected in processes established to respond to the crisis.
    - Affirm that the appropriate values are being applied in decision making and explain why those values are defensible.
- Support health care providers by publicizing the role that ethics has played in structuring responses.
- Speak to values that were incorporated in the development of the response and reassure groups and individuals, particularly those with concerns about equity, that their needs and concerns were heard and accounted for in the final plan.
- Advertise that they are available to discuss ethical concerns and challenges as they arise for those making decisions and providing care.

<u>After</u>

- Contribute to the important opportunities for reflection, analysis, and learning.
- Employ the process of reflective equilibrium by using experiences to revise judgments about relevant procedural and substantive values.
- Inform planning and preparation for subsequent crises.
- Address the moral distress that is likely to arise for HCPs who are directly or indirectly involved with implementing pandemic response plans.

<u>Conclusion</u>

With their guidance in making decisions, institutional ethics service can help to protect the front liners HCPs from self-guilt and spiritual crisis by reducing the degree of moral burden facing them. Even though the moral distress experienced by HCPs can be alleviated through shared responsibility in decision making with the help from ethics service, it is important to recognise that the HCPs are still the front liners and will have a primary duty of care towards their patients. They are the ones who will physically attend to patients in a life-threatening condition and grief-stricken family members. There is a possibility that some of them will suffer emotional or spiritual trauma, and therefore, psychological support service is also an important measure that should be in place.

Ultimately, the collective obligation of institution ethics services such as clinical ethics committees and clinical ethics consultation services is to minimize the number of difficult choices that HCPs must make in a pandemic (Warren, 2020). This role is best played in planning and preparing to face the pandemic, but are equally significant during and after the pandemic.

Some Institutional Ethics Services currently available in Malaysia:

1. IJN Clinical Ethics Committee
2. Hospital UiTM Clinical Ethics Consultation Services
3. Clinical Ethics Malaysia (CEM) COVID-19 Consultation Service

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CHAPTER 12

Triaging Protocol For ICU Admissions/Beds/Ventilators During Resource Crisis

Patrick Tan Seow Koon, Tan Hui Siu

When resources are at a critical stage, clinicians will need a triaging protocol to help them prioritise treatment and level of care based on the needs of individual patients and their response to treatment(1,2). Without the presence of triage protocols or guidelines, significant **moral distress** is likely to arise as healthcare professionals may need to adhere to population needs by providing or withholding treatment over the objections of patients or their families.

Please refer to Chapter 4 on the Literature Review of the Ethical Framework for Resource Allocation.

A. Transparent Decision-Making

During a Pandemic,

1. Critically ill patients form a trust bond (fidelity) with a doctor, which morally obliges the doctor to do their best in the interest of the individual patient. This may include a decision that the patient requires treatment, such as a ventilator and admission to an ICU bed(3).
2. It is legal and ethical to prioritise treatment among patients(4)
3. The decision-making process must be managed by experienced professionals, with responsibility borne by the most senior person present. Multidisciplinary support may be helpful in decision making(5)
4. Triage decisions proposing the collective good of society – utilitarian ethics – may be prioritised over individual autonomy, privacy, informed consent and refusal, and family wishes.
5. Fair rationing criteria and fair processes must be transparently applied, communicated with each patient and family and documented at all times,
6. Clinical decisions on the allocation of resources may be challenged subsequently by patients and family on issues of possible discrimination. Mechanisms for subsequent review of conflicts should be in place(6).
7. Any system put in place must be reviewed regularly for revisions based on the latest evidence, and also audited(7).

Ideally, patients admitted will have the following understandings. If they are not in evidence, the decision can be made and be documented.

- Patient acceptance of the broad scope and objective of ICU treatment,
- Patient acceptance of triage assessment by ICU specialist every 48 hours during life-support treatment,
- Patient willingness to accept that ICU organ support treatments may not be accompanied by improvement in organ function and survival chances and may

be accompanied by deterioration in organ failure following a finite but unspecified trial period of ICU life-support treatment,

- Patient willingness to accept palliative care and withdrawal of ICU life-support treatment when the patient's evidence of non-improvement or continued deterioration in organ function suggests that palliative care should become the most appropriate, humane and ethical method to provide care for the patient.

B. Literature Review of Several Articles on Triaging Protocols for COVID-19

I Robert Truog et al. article: "The Toughest Triage," meant for COVID-19, it was suggested that "rationing to be performed by a triage officer or a triage committee composed of people who have no clinical responsibilities for the care of the patient (2), in which triage proceeds in three steps:

- Application of exclusion criteria, such as irreversible shock;
- Assessment of mortality risk using the Sequential Organ Failure Assessment (SOFA) score, to determine priority for initiating ventilation; and
- Repeat assessments over time."

II Malaysian ICU Management Protocols, Ministry of Health and Malaysian Society of Intensive Care, 2019(8) (page 2-3, excerpts)

"1. ICU admission criteria

To optimise ICU resources and improve outcomes, ICU admissions should be guided on the basis of a combination of factors:

- Prioritisation according to the patient's severity of illness
- Specific patient needs such as life-supportive therapies
- Diagnosis
- Prognosis
- Potential benefit from interventions
- Objective parameters at the time of referral
- Available clinical expertise
- Bed availability

2. ICU admission based on priority

In evaluating the appropriateness of ICU admission, the priority should be based on the needs of the patient and the likelihood of benefitting from admission. This prioritisation defines those who will benefit most from ICU (Priority 1) to those who will not benefit at all (Priority 3) (Appendix 1)

3. Triage is the process of placing patients at their most appropriate level of care. It is often needed as the number of potential ICU patients exceeds the availability of ICU beds. Appropriate triaging allows effective bed utilisation and resource management. Factors to consider when triaging include:

- Likelihood of benefit
- Prognosis
- Life expectancy due to disease
- Anticipated quality of life"

III Islamic Bioethics Guidelines and Fatwas

These guidelines have supported a systematic and transparent triaging with clinical decision tools or triaging officers/committees, of which it includes the prohibition of withdrawing life-saving support to benefit the next patient but not if brain death or futility. There are considerations to advanced directives, altruism, random allocation, and healthcare workers in the flowchart by CILE (Appendix 2). Some of the excerpts of the Fatwas are noted here:

- **The European Council for Fatwa and Research (ECFR)** issued a fatwa (number 30/18): "Muslim physicians should comply with the administrative and medical regulations adopted by the hospital in which they work. However, if the decision is assigned to them, then they must utilize medical, ethical and humane principles. Withdrawal of life-saving equipment in order to benefit a patient coming after is not permitted. If the physician has no choice but to choose between two patients, then the first patient should be chosen (unless their treatment is deemed futile) and the patient requiring emergency treatment (over the patient whose condition is not so critical) and the patient whose successful treatment is more likely (over the patient whose successful treatment is unlikely). This is in accordance with fiqhi principle "ghalabatal-ẓunūn" and medical assessment(9)."

- **The Assembly of Muslim Jurists of America** issued a fatwa on 4th Aprio 2020 parts of the texts: "Human beings have the same intrinsic value...it is not permissible to favor some individuals receiving scarce resources over others...What is to be considered in prioritizing some over others is the degree of need; so the one in greater need should be prioritized, and if they have the same need (i.e., requiring the intervention for survival), the one with a greater likelihood of recovery, based on evidence-based clinical decision tools, should be given precedence. If such likelihood is equal, then those with the longer life expectancy should be given precedence. This is all consistent with the principle of 'procuring the greater good by forsaking the lesser.'...When applicable, service should be provided on a first-come, first-served basis...except when it may lead to stampedes or violence, or give unfair advantage to those capable of arriving early at a healthcare facility...If all previous considerations do not give precedence to some over the others, resorting to lottery is a principle that is endorsed...It is permissible for some people to decline placement on the ventilator, if it's benefit is questionable...(10)

- **The Research Center for Islamic Legislation and Ethics (CILE)** issued a flowchart (Appendix 2) its guidelines and stated that: "The state of hardship a pandemic causes does allow certain things that are normally forbidden. Clear pre-specified guidelines should be prepared as part of every disaster plan, publicly shared and instituted early to effectively manage limited resources throughout the pandemic with transparency and uniformity. The suggested algorithm is based on Islamic bioethical principles and balances utility with equity. It is designed to save the greatest number of lives without disadvantaging the vulnerable. Withdrawal is decided upon the consensus of a non-clinical team and is reserved for cases of brain death or futility. Muslim physicians are advised to follow the policy of their institutions and regulating medical bodies. If religious conflict with withdrawing or withholding life support is perceived, conscious objection may be considered(11)."

C. A Proposed ICU Triaging Protocol for Malaysia

Special Note: This section is to be read as part of a triaging protocol, of which the need to activate it is ONLY as a last resort during resource crisis.

Table 9 Proposed ICU Triaging Protocol for Malaysia during Resource Crisis

Safe and Ethical ICU/PICU Triaging (SET) Protocol for COVID-19
This process includes both CLINICAL and ETHICAL considerations

1. TWO intensivists (one who has no clinical responsibilities for the care of the patient)*.

2. B**efore ICU admissions, the** same assessment criteria are applied equitably*:
    a. Application of exclusion criteria, at least one pre-existing severe co-morbidity such as:
        - Cardiac arrest without return to spontaneous circulation despite defibrillation and cardiopulmonary resuscitation
        - Brain stem death
        - Hypoxic encephalopathy or persistent vegetative state
        - No improvement in respiratory or hemodynamic status, or underlying organ dysfunction.
        - Disseminated malignancy
        - Severe sepsis that has not responded following antimicrobial treatment
        - Persistence or development of triple acute organ failure
        - Children or neonates with underlying life-limiting congenital malformations
    b. Assessment of COVID-19 mortality risk by clinical judgement with or without other tools:
        - Short term survival scale: Sequential Organ Failure Assessment (SOFA) score or Paediatric Logistic Organ Dysfunction Score Calculator (PELOD-2) to determine priority for initiating ventilation;
        - Long term survival capacity (following recovery) and life cycle scales;
        - ICU admission based on priority (Malaysian ICU Management Protocol 2019), page2-3
    c. Consideration for the patient or patient's legal surrogate on Advanced Care Planning (ACP) or Advanced Directives (AD) decision made earlier to refuse intensive care admission or life-support treatment.

3. **Repeat assessments over 48-72 hours** (subject to clinical judgement) for evidence of deterioration in health status, or no improvement to treatment, or the patient has the desire to limit treatment, by the similar approach as above*. Clinical judgement is needed to evaluate the response/futility to treatment and to re-consider the benefits of life-saving measures -- especially for those with prior severe co-morbids or terminally ill patients.

For patients that did not receive intensive care or a decision of withdrawal of care is made:

- Each decision is communicated to that patient and family by the intensive care/medical doctors
- Each decision is documented.
- Palliative care* or other compassionate care* are provided.

Other steps to ensure safety and transparency:

- Oversight through mortality audits or other reviews at the hospital/state/national level.
- To consider clinical ethics consultation for complex cases or policy-making deliberations.
- Revision of this triaging system to be revised regularly according to the latest evidence.

Please refer to Chapter 15 on Communication, Chapter 16 on Redefining Compassionate Care, and Chapter 14 on Palliative Care.

In a pandemic situation when resources scarcity have reached a critical stage, the time and opportunities to deliberate on the decision to withdraw care or to revise the goals of care through an informed decision by the patient, team consensus, and family conference (or even an ethics consultation) may not be present. Thus, ethically, **it is acceptable to consider a different flow of decision-making, which is safe, transparent, and just.** For example, a decision to withdraw care could be made by two specialists, decisions communicated to family in an empathetic way, and compassionate and palliative care steps to follow. This expedited process through a "triage protocol" must be agreeable by the intensivists, emergency physicians, adult physicians, and infectious disease specialists at a national level, with ethics facilitation, auditing process, and regular revisions in place. The proposed “Safe and Ethical Triaging (SET)” for COVID-19 (Table 9) applies both clinical and ethical considerations and serves as a good start for such a discussion.

D. Further Explanation on “SET”

Some of the following existing objective clinical measures have been shared in the international journals and recommended for triaging purposes during the pandemic. Caution must be applied, as ultimately, they are just tools, and sound clinical judgement must be exercised.

I Assessing mortality risks through short term survival

A patient’s physiologic severity at the time of referral, laboratory investigations, age, and mortality prediction – in Sequential Organ Failure Assessment (SOFA) – may be applied to assign a priority score, equating to the capacity to benefit in short term survival(12,13). Paediatric patients may be scored the Paediatric Logistic Organ Dysfunction Score Calculator (PELOD-2)(14). Caveat: clinical measures and laboratory results must be readily available.

II Assessing mortality risks through long term survival and life cycle

A patient with severe comorbid conditions with death likely within 1 year is assigned a score of 3 points(15). See Table 10. Patients with younger age are given fewer points than persons with advanced elderly age(15). See Table 2 next page.

III Assessing for exclusion criteria

Decisions to recommend withholding of ICU admission to initiate or continue life support for respiratory and/or other organs for a patient can be made by at least two specialists, on any of the following evidence of exclusion criteria:

At least one pre-existing severe co-morbids(16) such as:

- Cardiac arrest without return to spontaneous circulation despite defibrillation and cardiopulmonary resuscitation
- Brain stem death
- Hypoxic encephalopathy or persistent vegetative state
- No improvement in respiratory or hemodynamic status, or underlying organ dysfunction.

- Disseminated malignancy
- Severe sepsis that has not responded following antimicrobial treatment
- Persistence or development of triple acute organ failure

Table 10 Biddison Proposed Strategy for Ventilator Allocation

TABLE 1] Proposed Strategy for Ventilator Allocation in Epidemics of Novel Respiratory Pathogens

Principle	Specification	Point System			
		1	2	3	4
Prognosis for short-term survival	Adults (SOFA) or pediatrics (PELOD-2)	SOFA score ≤ 8	SOFA score 9-11	SOFA score 12-14	SOFA score > 14
		PELOD-2 ≤ 12	PELOD-2 12-13	PELOD-2 14-16	PELOD-2 ≥ 17
Prognosis for long-term survival	Prognosis for long-term survival (assessment of comorbid conditions)	...	...	Severe comorbid conditions; death likely within 1 y	...
Secondary consideration					
Lifecycle considerations	Prioritize those who have had the lease chance to live through life's stages (age)	Age 0-49 y	Age 50-69 y	Age 70-84 y	Age ≥ 85 y

Examples of severe comorbid conditions with associated life expectancy < 1 year are listed. This list is meant as a guideline and is not exhaustive. Patients meeting the criteria of < 1 y predicted survival based on what of the listed or other similar conditions should be assigned a score of 3. NYHA = New York Heart Association.
1. NYHA class IV heart failure.
2. Advanced lung disease with FEV_1 < 25% predicted, total lung capacity < 60% predicted, or baseline P_{AO_2} < 55 mm Hg.
3. Primary pulmonary hypertension with NYHA class III or IV heart failure.
4. Chronic liver disease with Child-Pugh score > 7.
5. Severe trauma.
6. Advanced untreatable neuromuscular disease.
7. Metastatic malignant disease or high-grade primary brain tumors.

IV Advanced care planning

Patient or patient's legal surrogate may have made an advanced care planning (ACP) or advanced directives (AD) decision to refuse intensive care admission for life-support treatment, and this needs to be discussed considerably between the two specialists and the family to ensure that expectations in the goals of care are **clarified** and aligned.

Once this decision is made, it must be communicated to the patient and family by the intensive care/medical doctors with empathy and respect; each decision is to be documented; palliative care or other compassionate care is to be provided for ill patients or patients who did not receive ICU admission; and to consider clinical ethics committee for complex cases or policy-making deliberations.

V Repeat assessments over time

Patients already admitted in ICU should be assessed every 48-72 hours for evidence of deterioration in health status, no improvement/response to treatment, or the patient has the desire to limit treatment. A clinical decision to reconsider the benefits of treatment of life-saving measures should be made for those with previous severe co-morbids or terminally ill patients. This revision in the goals of care includes the withdrawal of therapy and the provision of palliative care.

VI Patients not receiving intensive care

Once the decision is made that intensive care is not in the best interest of the patient, it must be communicated to the patient and family by the intensive care/medical doctors with empathy and respect; each decision is to be documented; palliative care or other compassionate care is to be provided.

VI Other considerations

1. Increasing age factor(17):
   - is not an independent criterion for acceptance or denial of intensive care admission for life-support treatment,
   - is a weightage criterion, together with the severity of illness criteria, in the strength of recommendation for ICU admission to receive life-support treatment.

2. Pregnant women (will be rewarded more points with a healthy fetus)(18) and NICU admissions are be covered in this version of the guideline.

3. Simultaneous or intermittent sharing of oxygen equipment or ventilator for more than one patient at the same time is dangerous for patients, impedes healthcare workers' ability to deliver safe care for the patients, and is contraindicated(19).

Please refer to Chapter 15 on Communication, Chapter 16 on Redefining Compassionate Care, and Chapter 14 on Palliative Care.

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CHAPTER 13

Resuscitation In The Era Of COVID-19

Liew Houng Bang, Tan Hui Siu, Chan Lee Lee, Hafizah Zainal Abidin

Key Points:

- During this COVID-19 pandemic, healthcare workers (HCWs) in many countries have been infected and some have died.
- Cardiopulmonary Resuscitation (CPR) involves aerosol-generating procedure (AGP), which may involve manual bag-mask ventilation, emergency tracheal intubation, and airway suction. AGPs pose a very high risk of virus transmission to HCWs.
- CPR may not be beneficial or effective in some situations.
- HCWs have an ethical duty to protect themselves and their colleagues during resuscitation.
- HCWs are recommended to proactively anticipate, prevent, and prepare for various CPR scenarios.
- Do-Not-Resuscitate (DNR) decisions should be considered for terminally ill (poor prognosis) and dying (physiological futility) patients and must be part of the "difficult conversations" that comes along with the revision in the goals of care, with clear and empathetic communication with patients and families.
- Consultation and team consensus decision-making is encouraged when there is a dilemma.

A. Introduction

COVID-19 is highly infectious, spreads rapidly, and is potentially deadly, with no proven therapeutic modalities. There are more than two million confirmed cases worldwide since December 2019. At the time of writing on 16 April 2020, the global fatality rate is 6.7%, and as high as 13-14% in some countries e.g. Belgium, UK, and Italy. The critically ill COVID-19 patients manifest with respiratory failure and shock, with consequences of hypoxia and arrhythmia. In Italy, more than 100 doctors have died. In Malaysia, as of 23rd April, there have been 325 HCWs infected (5.8%).

During resuscitation, there is an exceptionally high risk of COVID-19 infection to HCWs due to the need for AGPs. Lack of or breach in PPE is a known risk factors of higher infection and mortality rates among infected HCW. Before COVID-19, most resuscitation protocol did not incorporate the need for strict PPE usage in most clinical settings.

In response to COVID-19, the UK Resuscitation Council introduced a modified version of the adult ALS resuscitation algorithm for COVID-19 patients(1) (Appendix 4). The American Heart Association (AHA) published an Interim Guidance for HCWs with a dedicated section for Emergency Medical Service (EMS) and other first responders(2)

(Appendix 5). There is another article published by the American Medical Association (AMA) on Addressing Advance Care Planning and Decision about DNR Orders during COVID-19, introducing a proposed framework for informed assent(3) (Appendix 6).

Preparedness is key. All HCWs, especially frontliners, need to know and anticipate the possibility of being in several scenarios, as will be discussed as follow.

B. Overarching Agenda

1. **Adherence to appropriate PPE** and other protective gear or measures MUST be strictly observed during resuscitation. Specific steps and areas for donning and doffing as per MOH and institutional guidelines must be followed. **"SAFETY COMES FIRST"** during the care of patients with COVID-19. This is in line with evidence-based medicine, workplace safety governance, and rational scientific and ethical reasoning. Special equipment and added protective gear such as Powered Air-Purifying Respirators (PAPR) are recommended during resuscitation.

2. **Anticipation of arrest is critical** to ensure the safety of both patients and HCW. Vital signs monitoring equipment must be functional and reliable to alert the team.

3. **Adequate preparation and training must be in place** e.g., drills to familiarize with special equipment, handling individual task in appropriate PPE, and various CPR scenarios. Clear identification of the level of care and expertise during resuscitation, aligned with international and/or local ICU/PICU guidelines for COVID-19 (Appendix 7).

4. **Effectiveness of resuscitation** could be achieved by having a specific team for resuscitation such as a Special COVID-19 Code Blue System, which may help in ensuring the safety and effectiveness of the resuscitation process.

5. **Timeliness of resuscitation in unanticipated cardiorespiratory failure or arrest**, to consider:

    - The time needed to don PPE (including PAPR). For example, while awaiting staff to don PPE, avoid bagging to prevent aerosol generation. Hands-only CPR and cover patient's mouth with a face mask to minimise aerosol generation.
    - The time needed to transfer such patients to a dedicated room with negative pressure and preparation of equipment.
    - When SpO2 is very low PPV may be performed as long as PPE has been donned by all in the room and a viral filter inserted between the bag and mask.
    - It is advisable to attach adhesive pads for external defibrillation on all patients with a high likelihood of ventricular arrhythmia to minimize the delay for defibrillation. Successful defibrillation rate is highest within the first minute, i.e. 90% and drops by 10% with every minute delay.

6. **Ethical decision-making.**
   Some of the ethical principles to guide in resuscitation include(4) (Table 11):

Table 11 Thompson AK et al. - Ethical Principles in the Discussion of Resuscitation

Principle	Description	In the Context of Resuscitation
Duty of care	The duty to provide care and respond to suffering. It can only be fully achieved when clinicians perform in a safe environment, with the right equipment and skills. Universal precautions are usually observed during resuscitation.	Don appropriate PPE as recommended by MOH and/or local institution standards during COVID-19 pandemic.
Proportionality	The measures that are taken to ensure the safety of HCW should not compromise the level of patient care. Patient level of care should be in proportion to the level of suspicion and risk.	Adopt different algorithms or measures when handling different groups of patients (COVID-19, unconfirmed but suspected COVID-19, low probability, or non COVID-19).
Equity	All patients have an equal claim to receive needed healthcare. Ensure procedural fairness in decision making.	Provide routine steps for resuscitation of non-COVID-19 patients as per protocol. Ensure equity of outcomes by providing proper palliative or end-of-life care for terminally-ill or dying patients.

C. Other Ethical Contexts to Consider:

1. The **need for closure** among surviving family members to see that "all appropriate treatment has been given" by witnessing or knowing that CPR has been performed.
2. The ethical acceptability of **"unilateral decision-making"** ("moderate paternalism") by attending physicians/specialists, based on best interest principle, especially in an emergency or in the absence of a surrogate.
3. The **public expectations and external pressure** towards HCWs to perform CPR and save all COVID-19 patients.
4. The **physical and emotional burnout** among clinicians during the pandemic, causing misjudgement and "jumping in" to resuscitate without consideration of personal safety.
5. The **medical unfamiliarity** with a new virus and a pandemic situation that requires HCWs to learn and relearn resuscitation protocols and the right coordination of teamwork; and to keep up-to-date with the latest development.

D. Decision-Making Flow to Consider Do-Not-Resuscitation for Malaysia

Figure 3 Proposed Flow for DNACPR adapted from Randall Curtis J, JAMA(3)

Decisions for DNACPR for COVID-19 patients in a semi-acute setting or anticipated arrest in the hospital by TWO specialists if:

- The patient is in a *physiological futility* state (i.e. vital signs are deteriorating despite maximum ventilation and inotropic support), OR
- The patient is terminally ill and CPR is not in the best interest of the patient, OR
- The risks of CPR outweigh the benefits to the patient, OR
- If a decision has been made by the patient or family earlier.

AND

DNACPR decisions must be part of the "difficult conversations" with clear and empathetic communication with patients and families.

Difficult conversations (Table 2) must be held with family as early as possible, by senior members of the team, and preferably face-to-face (in person or video call).

AND

HCW needs to consider palliative care for ill patients.
Palliative care consultation may be helpful in management plans related to symptoms management and realigning the goals of care.

Please refer to Chapter 14 on Palliative Care, Chapter 15 on Communication, and Chapter 16 on Redefining Compassionate Care.

Table 12 How to talk about non-beneficial CPR with families, adopted from Randall Curtis J, JAMA(3)

Discuss CPR	How, when, and why it is performed	*"We want to be sure we are taking the best possible care of your mother, so I would like to talk to you about CPR*
Summarize the role of CPR	The ability of CPR (or lack thereof) to achieve patient's goals	*"Given what you have told me about your mother and her goals, CPR will not help her reach her goals."*
Present a definitive assent statement	Inform the patient or the patient's family that CPR will not be offered	*"Since CPR will not work to achieve your mother's goals in this situation, we do not provide it."*
Assess understanding	Discuss the patient's or family's understanding of the decisions made, and any objections they may have	*"I want to make sure you understand. Do you have any questions?"*

E. Conclusions

It is important to realize the uncertainties during these unprecedented times. HCWs must be ready to adapt to the various situations; and to be willing to engage in discussion and formulate, modify, or adapt to new guidelines or recommendations to optimize care. Bedside decision-making dealing with life and death under time pressure can be challenging, and therefore early consensus among senior members of the clinical team is essential with the consideration of ethics support, if available.

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CHAPTER 14

Palliative Care During The COVID-19 Pandemic

Chong Lee Ai, Azanna Ahmad Kamar, Richard Lim Boon Leong

"8-year-old ZR has metastatic cancer and is bed-bound at home. He has been taking morphine more regularly now for his headaches. Tonight he can't pass urine, his mother wants to bring him to hospital but ZR has had enough of hospitals and just wants to remain home. With the COVID-19 lockdown, home palliative care nurses had to stop their night visits. The on-call nurse advises mother over the phone, also promising a visit first thing tomorrow morning. Both mother and father are in distress, watching over ZR who is in discomfort. Nobody in that house slept that night...."

Key Points:

- Public health priorities and resource availability may restrict patient's decisions and compromise care delivery.
- Palliative care needs to be integrated into the current healthcare response to COVID-19 crisis.
- Palliative care principles should be applied by all health care providers.
- Palliative care is imperative for those not eligible for life-sustaining therapies

A. What is Palliative Care?

For patients with life-limiting illnesses and their families, palliative care aims to mitigate suffering be it physical, psychosocial and/or spiritual and maintain a quality of life of meaning specific to them.[1] Palliative care is not just applicable when treatment for the underlying disease fails and/or dying is imminent but the approach to care should begin at diagnosis and continue through the illness until death and bereavement.

Open and honest communication, relief of distressing symptoms, respect for patient's choice aligned with their goals, promotion of comfort and the support for the patient and their family are key palliative care principles which also reflect ethical clinical practices.

Palliative care offered only at the end-of-life will miss opportunities to reduce suffering during the illness journey

B. Global COVID-19 Crisis

Consequentialism and utilitarianism are both common ethical approaches used in a pandemic for the best public health outcome.[2] In this global crisis, Malaysia and many countries in the world have adopted movement control orders (MCO) and social distancing for the greater good.[3] This measure however has caused additional burden to patients and their families.

As our healthcare systems tries to cope with the number of patients that require care and the increasing number of deaths from COVID-19 individual suffering may be lost in the chaos. We need an equitable healthcare system that is responsive to all patients with palliative care needs.

We discuss the delivery of palliative care to patients, both with and without COVID-19 and its implications to healthcare providers (HCP).

C. Patients Who Are COVID-19 Positive

Patients who are deteriorating clinically from COVID-19 face a life-threatening situation from the illness itself and possibly exacerbated by un-equitable services. The unexpected possibility of them facing premature death is a reality. Wherever patients may be, it is imperative that palliative care is provided based on the ethical principles of beneficence and non-abandonment.

As healthcare professionals strive to attend to the disease and remedy the pathophysiology of the patient with medicines, oxygen, intensive care and ventilatory support, we must remember our role as healers. Palliative care interventions which aim to alleviate suffering and uphold dignity should occur together when managing the potentially fatal infection. [4,5]

The separation from loved ones that rarely occurs when one is sick and the loss of 'human' contact with your doctors and nurses who are masked with face shields and covered from head to toe can be daunting. Attempts to reconnect personhood with the surroundings and personalising care is the duty of healthcare providers.

> Our duty to not just treat the infection but the whole person with dignity

D. Challenges to Communication (Quarantine, Personal Protection Equipment (PPE), Social distancing)

Skillful communication can help identify and assess the domains of suffering experienced by patients and their families. Compassionate psychosocial, emotion and spiritual care can still occur despite isolation. When visits are restricted, innovative ideas and simple and inexpensive technology can facilitate communication between healthcare providers, families and patients, irrespective if they are in hospital, healthcare facility, or home.

Communicating with our eyes through the face shield or face mask, the tone of our voice, our body language and our gloved hand-touch can be our greatest tools. Clear, honest information provided in an empathetic manner at an appropriate pace can help relieve fear, anxiety or anger.

Although technology may facilitate communication, the absence of good face-to-face companionship with loved ones may result in feelings of helplessness and desolation. Psychosocial, emotional and spiritual needs should be assessed daily and attended to.

For vulnerable groups (eg. young adults with special needs, persons with specific psychiatric needs, elderly with visual or hearing impairment) special arrangements should be made for carers to be present. In these circumstances, the risks and limitations of being with a loved one with COVID-19 should be fully explained and informed. Young children should not be separated from their parent or carer. Carer's access to restrictive resources (eg. PPE) must be discussed and balanced with the psychosocial well-being of the patient.

Table 13 Proposed Innovative Ways to Communicate during COVID-19 Pandemic

Communication	Media/Application	Tool (with a cover that can be sanitised)	Users
Real time communication	- Voice or video (eg. Whatsapp calls, Facetime, Zoom, Skype) - Words or photos (whatsapp, telegram,) - Drawings/ diagrams	- Mobile phone - Tablet	- Patient - Family - HCP - Family - HCP - Patient
Recordings to be replayed when convenient	- Voice messages - Video recordings - Photos (family, friends, pets)	- Mobile phone - Tablet	
Permanent messages	- Words - written - Word/Picture Magnets - Drawings - Sketches	- Communication board strategically placed in the room - Specific treasured items - Items with special meaning - Face shield	- HCP - Patient - Family - Patient

Communication	Media/Application	Tool (with a cover that can be sanitised)	Users
Real time communication	- Voice or video (eg. Whatsapp calls, Facetime, Zoom, Skype) - Words or photos (whatsapp, telegram,) - Drawings/ diagrams	- Mobile phone - Tablet	- Patient - Family - HCP - Family - HCP - Patient
Communication with children	- Play - Infographs - Videos - Animated videos	- Favourite toy/game - Informative videos appropriate to developmental age	- HCP - Patient - Parent - Patient

E. Patients Without COVID-19

Professional ethics guides us to be healthcare providers with integrity and we have fiduciary duty to all our patients. We need to be mindful of the vulnerable groups of patients (eg. children, patients with no family, patients in nursing homes) who may not receive equitable care in the current restrictions imposed to the healthcare system. Patient with palliative care needs who would normally be seen at hospital are now not coming for fear of acquiring the potentially deadly virus. Symptoms may be left till very late before seeking medical attention. Special considerations and changes to hospital policies are required to ensure patients feel safe to come for consultations.

Patients and families receiving home palliative care may receive fewer visits with the reduction of face to face interactions with the movement restriction order (MCO) in place. A system in place to ensure fair access of personal protection equipment (PPE) for all healthcare providers is required to ensure safe and continued healthcare encounters.

Continued access to medications for symptoms controls especially controlled medications (eg. opioids) needs to be maintained. Collaboration with hospital pharmacists can help ensure patients receive adequate supply of medications.

F. Goals of care

Palliative care helps facilitate patient's advanced care plans, addresses anticipatory grief and helps reframe their goals when they are at the end of their disease trajectory. For patients with co-morbidities and additional burden of severe COVID-19, clarification about previously discussed advanced care plans will be helpful in formulating a patient-centred management care plan. The dilemma to treat COVID-19 infection in a patient at end-of-life should be resolved by discussing the goals of treatment with the patient and family members of patient's choice, especially if the treatment concerned is experimental or trialled.

When patients (COVID-19 positive, under investigation-PUI, severe acute respiratory infection-SARI) are quarantined, surrogate decision makers or extended family members are not allowed by their bedside. Hence shared decision making for important end-of life care plans (e.g. withholding or withdrawing life-sustaining support) will be challenging.

Therefore, early identification of the need for a palliative care referral and its timely integration, especially for patients with co-morbidities and those with severe acute respiratory infection (SARI) may facilitate an understanding of goals of care prior to the need for invasive ventilation and a smoother illness journey for them.

Asking open-ended questions and developing listening skills are helpful to identify patient's needs and wishes. The mnemonic REMAP helps forms a framework for the complex conversations required for a patient-centred goals of care.[6]

R Reframe - *assess understanding, provide new information and the 'big picture', justify need to evaluate goals*
E Expect emotions - *attend to emotional response*
M Map out patient values - *explore patient's values*
A Align with values - *match values with goals*
P Propose a plan - *define a patient-specific plan*

Please refer to Chapter 15 for Communication and Appendix 8 for further REDMAP scripts.

Being present and developing listening skills are useful to understand patient's values, goals and preferences

G. End-of-Life Care and Bereavement

The movement control order (MCO) has affected both groups of patients, with and without COVID-19. Patients who wish to do purposeful travel or visit families are now unable to do so. An alternative, albeit a less than a satisfactory one, are virtual trips with technology that help connect people with places.

The uncertain duration of MCO can create anxiety and fear, especially amongst those with a short prognosis, of their unfulfilled wishes. For surviving relatives there may be the regret of an unfulfilled wish or task resulting in complicated grief in bereavement.

Common symptoms associated with COVID19 (eg. breathlessness, cough, fever, delirium) and other symptoms of their underlying illness should be treated to ensure comfort.[7] Consider both non-pharmacological and pharmacological strategies for treatment of symptoms.

The just distribution of ventilators and resuscitation requires ethical reflection within the local context and may differ in regions within a country. Withdrawal or withholding

of life-sustaining support doesn't exclude compassionate care and this is a time when palliative care is most required.

Preparations for end-of-life have to be modified during this pandemic. For those unaffected by COVID-19, a peaceful death with symptoms managed, surrounded by loved ones may not be possible in hospital but safe home death should be facilitated as far as possible.

When death is imminent in hospital, restriction of visitors to hospitals prevents last visits or their last hug from husbands, wives, children, grandparents and favourite relatives. It will be something we all will have to live with for the rest of our lives.

The COVID-19 pandemic quarantine have changed the norms of dying. We should try to ensure patients, amid the chaos, do not die alone or with burnout healthcare staff. As ethical healthcare professionals, we have a moral imperative to provide quality end-of-life care for the dying including their spiritual needs. As far as possible consider the use of technologies to help families interact with their loved ones who are in isolation[8].

Fulfilling a wish from a patient or from a loved one with PPE, to accompany a dying patient, should be discussed with hospital authorities. A last most treasured touch and the presence of a loved one may reduce fear and anxiety at death and reduce complications in bereavement.

Critically ill children with COVID-19 may be a minority but the suffering of these children should not be theirs to be borne alone. No child should be left to die alone.

The important rituals and social support at funerals and during mourning often present as opportunities for closure, but this has change during this crisis. Funerals for those who are COVID-19 negative are restricted to a few attendees. Families of those who die from COVID-19 are separated from their loved ones from diagnosis, and some till burial if they themselves needed to be quarantined.

The last rituals of patients with COVID-19 will not be `normal' burial rituals, and this transcend across all cultures. The presence of normal communal prayers, religious heads and close family members are all omitted. A body wrapped in plastic is not the norm for most religions, and in some countries, cremation has been proposed to be mandated.[9]

Bereavement follow-up will be even more important in this crisis and we may expect increased rates of complicated grief. Active steps to acknowledged and addressed families grief and avenues to seek help should be made available.

H. Healthcare Professionals

Healthcare providers need not only disease specific knowledge but more importantly the availability of PPE with the skills training in meticulous preventive measures to avoid acquiring the infection from their patients. We rely on organisational ethics to guide hospital management to ensure the safety of staff who provide palliative care.[10]

Feeling powerless to prevent the deaths and suffering from caring with physical and psychological exhaustion can result in distress among healthcare providers. Moral distress from making complex decisions need to be acknowledged and addressed. Awareness and mindfulness of our own health and that of our colleague's are required to mitigate physical and mental exhaustion. Systematic surveillance of the well-being among front-liners and access to services to alleviate distress is just as important as their primary role in caring for patients.

Please refer to Chapter 17 on Moral Distress.

I. Recommendations [1,7]

1. **Early communication with the palliative care team if available at your hospital for:**
   - Patient already known to palliative care team
   - Children
   - Vulnerable or marginalized population
   - Complex symptoms with underlying morbidities
   - Symptoms not improving as expected
   - Decision not to escalate, poor prognosis
   - Withholding or withdrawal of ventilator
   - Patient imminently dying

2. **Role of palliative care**
   - Assessment and management of symptoms
   - Compassionate communication
   - Discussion about prognosis, goals of treatment and resuscitation status
   - Management of family's grief

3. **If palliative care team not available, apply palliative care principles**

- Address:
  - Symptom control
  - Psychosocial and spiritual assessment and management
  - Compassionate communication

Conclusion

Palliative care needs to be integrated into the health system responding to the COVID-19 pandemic. All patients who need care should receive it and it is unethical to let patients suffer needlessly. While economic and public health concerns are prioritised, the individual voice should not be lost in the chaos. Patients who are not expected to survive and their families must receive palliative care as a human right.

> You matter because you are you, and you matter to the last moment of your life.
> - Dame Cicely Saunders

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CHAPTER 15

Open And Effective Communication

Chan Lee Lee, Tan Hui Siu, Chong Lee Ai, Richard Lim Boon Leong, Sheila Gopal Krishnan

"A family waiting to see their loved one who has been admitted to the CCU as an emergency. The 67-year-old gentleman has presented earlier on with shortness of breath and fever for 3 days and diagnosed with Acute MI. His condition deteriorated as soon as he arrived at CCU. He is currently intubated and supported with double inotropes (Killip 4). His swab sample has been sent. Your hospital is facing a surge of COVID-19 cases. Resources (ICU/CCU beds, ventilator) are getting tight. Patient's COVID status is uncertain. He needs to be isolated. There is possibility that your team may consider withdrawing life support if patient is not improving."

Key Points:

- All patients (children, adolescents and adults) and their families have a right to accurate information at all times.
- Honest and compassionate communication can facilitate decision making at end of life.
- Non-verbal communication and technology can help overcome barriers from PPE.
- Open and transparent communication fosters trust and respect among team members.

A. Introduction

During COVID-19 pandemic, effective communication **between the physician and the patient**, **the physician and the surrogates (patient's family), and team communication** must be upheld as it is a benchmark of achievement of healthcare professionalism and part of physicians' duty of care towards patients and their team members-- fulfilling at least:

- the right to information
- a just and safe environment, and
- the avoidance of emotional and moral distress

When dealing with patients who are deteriorating due to underlying health problems and/or infection with COVID-19, **clear, sensitive, and respectful language** is needed, and barriers to effective communications acknowledged (as suggested in Table 14). Virtue ethics values like **honesty and empathy** are essential during ALL communication, including breaking of bad news or medical error, and when discussing end-of-life issues.

Table 14 Potential Barriers to Open and Effective Communication during COVID-19 Pandemic

Healthcare Providers	Patient or Family Members	Physical Barriers
1. Busy and occupied with clinical management 2. Fear and anxiety of being infected 3. Unfamiliar with clinical management protocols 4. Overall medical uncertainties 5. Inconsistency in care 6. Poor team communication 7. COVID vs non-COVID priorities	1. Fear and anxiety with the disease, isolation, and quarantine. 2. Stigmatization from the interrogation by HCP and loss of privacy. 3. Specific groups are being singled out for questioning and testing. 4. Marginalized groups may feel discriminated against for not receiving the standard of care.	1. **Masks/face shield** covering facial expression. 2. **Physical distancing** standing 1 meter away. 3. **Bulky PPE** restricting empathetic body gestures 4. **Tone of voice** cannot be lowered. 5. **Lack of private space** for difficult conversation (Non-verbal communication is a challenge due to the above. See section E.)

In terms of clinical governance, **transparency and accountability** are key principles in establishing trustworthiness at all levels. **Trust and trustworthiness are** essential for the implementation of various public health control measures(1). As part of risk communications, good communication helps to manage an individual's expectations and fears, encouraging people to trust and follow instructions during pandemic(2).

B. When Should the Task of Communication Take Place?

<u>Recommended SIX occasions</u> when the task of communication during COVID-19 Pandemic take place

- Isolation and quarantine process for COVID-19 patients or suspects(2,3)
- Breaking bad news and subsequent management plans
- Daily updates on progress.
- A sudden change of the patient's clinical status, of which a new update must be communicated to the patient or family at any time of the day.
- When a revision in the goals of care and realignment of expectations are needed – to take place as early as possible(4)
- When a request for more information by the patient or family members.

C. How and by whom?

Modified mediums are needed to update family given the restriction in visitation now that family members are not allowed to enter in wards/hospitals and some are themselves being quarantined or isolated somewhere else. Email or text messages to a patient's family to convey serious matters or bad news should be discouraged.

Difficult conversations: This must be held as early as possible, **by senior members of the team,** and **preferably face-to-face** (in person or video call). This includes family conferences. See RED-MAP below.

Simple updates: This could be performed through daily phone calls around the same time (give and take 1-2 hours), by the nurse-in-charged or medical officers, with clear updates or instructions **written or prescribed by the senior member of the team** to ensure accuracy and consistency of communication.

D. Aligning Emotions, Expectations, and Goals of Care

RED-MAP is a 6-step approach for conversations about deteriorating health and dying to align emotions, expectations, and the goals of care (Table 15). During COVID-19, difficult conversations must be held as early as possible, by senior members of the team, and preferably face-to-face (in person or video call). First few points are adopted from ec4h.org.uk(5).

- If talking with people by phone/video, check if you **have the right person**. Ask if it is a good time. Speak slowly, shorter sentences. Check what has been understood(5).
- Ask for **help and support** from colleagues, senior staff or a specialist. Seek a second opinion, or pastoral care/faith support if needed(5).
- Family might want some **important family member** to be involved in the conversations.
- **Avoid words and phrases** that can make patient feel abandoned or deprived of treatment and care(5).
    - *"There is nothing more we can do." "We are withdrawing treatment. Further treatment is futile."*
- **Be sensitive** when breaking bad news. Ensure the patient is ready to hear the bad news. Talk about what can be done for them, on the focus or goals of care that may have to change as the treatment you have tried is not working as expected. Talking too early about how drugs will not may not work or palliative care causes distress to certain patients.
- Consider **language and cultural norms**, faith support, relational aspect (who makes decisions), value and belief systems, and technology availability.

Table 15 RED-MAP (adapted from ec4h.org.uk - COVID-19: Effective communication for professionals)(5) – more scripts in Appendix 8

Ready	Try to build a relationship with people. Eye contact, touch and tone help when wearing mask. ***"Can we talk about your care and what COVID-19 might mean for you?"***
Expect	Find out what the person/family know and expect. Explore initial questions or worries. ***"What do you understand about this disease?" "Is there anything you would like to ask about the situation?"***
Diagnosis	Share information tailored to current understanding of the person/ family and their situation. Explain what we know in short chunks with pauses to check their response. Avoid jargon. Acknowledge and share uncertainty. Showing empathy makes a big difference to people. ***"What we know about COVID-19 is… What we don't know is… What we are not sure about is…"***
Matters	Pause to let people take in information. Find out what's important to this person/ family. ***"What matters to you the most right now?" "Is there anything we should know about how you would like to be cared for if you became very unwell?"***
Actions	Talk about realistic, available options for treatment, care and person/family support. Be clear about what will not work or help. Options depend on best place of care. ***"What we can do to help is… This does not work/help…"***
Plan	Use available forms and online systems to record and share care plans (and DNACPR decisions if applicable). ***"Let's make a plan for good care for you/your family."***

E. Non-Verbal Communication during COVID-19

Non-verbal communication is essential for effective communication(6), enhancing relationship, and building trust. Overwhelmed by the medical uncertainties, emotional and moral distress, workload, and other physical barriers (as in Table 14) during a pandemic, there is greater risk of suboptimal non-verbal communication, creating unwarranted misunderstanding.

Under a full-suit PPE, the lack of facial expressions (except for eyes), distance, and tone of voice will need to be overcome by more body gestures (Table 16).

Also, given that **phone calls or texts/emails** are less effective for non-verbal communications, these medium should only be reserved to simple updates or information, e.g. appointment time for family conference, transfer to step-down wards.

Table 16 Recommended Ways to Improve Non-Verbal Communication during COVID-19 Pandemic

Setting	Calm, private, non-interrupted, non-intrusive if possible
Attitude	Respectful, empathetic
Tone of Voice	Slower, reassuring vs apologetic
Effective Listening	Nodding, pausing, mirroring.
Gestures	Hand gestures • Thumbs up: “Good!”, “You are right!” • Okay sign: “Yes, I got it!”, “Ok!” • Wave: “Hi!”, “Bye!” • Hand to chest: “I am sincere”, “I am sorry”. • Glove pat: “You are ok!” Body gestures • Half bow: “I respect you”
Facial Expressions	Maintain good eye contact, smile with eyes (broad smile)
Other Novel Ways	Identification on PPE (names or photos)

F. Talking to Children on COVID-19

Children need information appropriate to their developmental age and maturity. Healthcare providers need to be able to listen and explore children's understanding of illness to address any fears and anxiety that they may have. “Answering, sharing facts and letting children know that it is fine to be upset or scared” are an important part of mental health support for families(7). Many animated videos for younger children and posters or infographics for older children are available to help explain COVID-19 to children. Some of the useful resources are:

1. Unicef 6 ways to deal with emotions: https://www.unicef.org/malaysia/stories/6-ways-parents-can-support-their-kids-through-coronavirus-disease-covid-19-outbreak
2. Harvard's Parental Guide - https://cdn1.sph.harvard.edu/wp-content/uploads/sites/2555/2020/03/Talking-to-children-about-the-impact-of-COVID-19.pdf
3. APA - Advice for caregivers of children with disabilities in the era of COVID-19: https://www.apa.org/research/action/children-disabilities-covid-19
4. Boston Children's Hospital – COVID-19 resources for families (including adolescents): https://www.childrenshospital.org/conditions-and-treatments/conditions/c/coronavirus
5. Applying palliative care principles to communicate with children about COVID-19:https://doi.org/10.1016/j.jpainsymman.2020.03.020

G. Saying Goodbye

Family's presence during the last moments is crucial for compassionate reasons. While dying occurs in the hospital/ICU setting, **family's presence** (in person or video call) helps surviving loved ones to come to better closure, and to mitigate guilt and grief – through:

- Involving directly in the patient's care
- Seeing that the best care has been provided, and
- Fulfilling that last wishes and accompaniment

Please refer to Chapter 16 on Redefining Compassionate Care and Chapter 14 on Palliative Care

Table 17 Center of Advance Palliative Care (CAPC) Toolkit on offering support for what to say to loved one who is dying "The 5 Things"

[Preview + Asking Permission]: *"Sometimes people wonder what to say when their loved one is dying. Is that something you are wondering about? Would it be helpful if I shared some things some people have found helpful?"*

If yes, then*: "Some of these things may apply to you, and others might not. There is no order and you can use any of these 5 things that feel right to you. We think that even though your loved one is sedated and comfortable, that many patients retain their ability to hear, even when they are unconscious. So, if you wish, this is the time to say good-bye. These are the 5 things to consider saying. You might want to write them down*."

1) **Please forgive me (for anything I may have done that caused you pain)**
2) **I forgive you**
3) **I love you**
4) **Thank you (for being my father…)**
5) **Goodbye**

Many patients worry about their families and whether they will be okay after they die. It helps some patients to be reassured that their family will take care of one another after the patient dies.

H. Team Communication

Uncertainties create fear even among HCW. Timely information and clear instruction from the team leader is required to maintain trust within the team. Leaders are required to proactively communicate what is known, what is unknown, and what is being done to get more information with staff, with the objectives of saving lives, protecting staff, and allaying emotional, psychological, and moral distress. Several ways to foster trustworthy include(9):

Table 18 Pan American Health Organization (PAHO) Guidelines for Communicating About Coronavirus Disease 2019 - A Guide for Leaders (9)

- Acknowledge uncertainty.
- Don't over-reassure. Don't minimize people's concern.
- Avoid stigmatization.
- Express empathy.
    - e.g. don't say, *"I know how you feel."* Instead say, *"It's natural to feel anxiety. This is a worrisome situation for all of us."*
- Acknowledge mistakes. Correct it if there is an error. That shows the human side and creates trust because you have not tried to hide information.
- Set expectations.
    - e.g. *"We expect things to get worse before they get better."*
- Acknowledge that the situation will change and explain that you will provide updates when there is more information.
    - e.g. *"This is an evolving situation and we will update you later with more details."*
- Be transparent. Ensure that the criteria for taking different actions are clear and available.
    - e.g. *"We are vaccinating this group first because they are at greater risk."*
- Explain the decision-making process.
- Detail what still needs to be learned and where the gaps lie.
- When guidance changes explain the reason why.

I. Sources on COVID-19 Communications Toolkit:

1. COVID Ready Communication Playbook (VITAL talk): https://www.vitaltalk.org/guides/covid-19-communication-skills/
2. Center to Advance Palliative Care (CAPC) COVID-19 Response Resources – Toolkit and online course: https://www.capc.org/toolkits/covid-19-response-resources/?fbclid=IwAR3FmucqAGvpIuYkGNl0ASsxrL-2hTkT_Gg1ci34lLME4eEtk9L7J0MFqy8
3. MOH mental health kit (infographics for COVID-19 patients or suspects): http://www.moh.gov.my/moh/resources/penerbitan/Garis%20Panduan/Umum%20(KKM)/Kit_Kesihatan_Mental_COVID-19.pdf

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CHAPTER 16

Redefining Compassionate Care During The COVID-19 Pandemic

Patrick Tan Seow Koon, Tan Hui Siu, Chong Lee Ai, Richard Lim Boon Leong

"A 2-week-old baby boy presented to the emergency department (ED) with severe septicemia and transferred to the NICU for further care. ED team was informed by the grandparents that the father of the baby was COVID-19 positive with mild symptoms, currently waiting for his second nasopharyngeal swab in a nearby tertiary hospital. The mother of the baby was quarantined at home. Grandparents were possible Persons Under Investigations (PUI) and were not allowed to accompany child. Upon further assessment in the NICU, a diagnosis of severe coarctation of aorta was made. Despite of maximal support, the baby deteriorated and was unstable to transport to the paediatric cardiology unit. The baby was dying, and HCP caring for the child felt helpless because of isolation and quarantine rules that forbade the parents to visit NICU. The baby passed away in the NICU without his parents."

Key Points:

- Compassionate care requires sensitivity to human suffering
- Compassion and trusting relationships are vital to patient-centred care
- Healthcare professionals have an ethical duty to preserve human dignity, and to consider the seven compassionate steps during COVID-19 pandemic.

Ethics of care arises from the sense of being responsible for others. Often the impersonal principles of justice and fairness overshadow the personal moral relationship. In health care, it is the health care professional's human emotions, capacity for empathy, sense of relationship with our patient that determines our moral response. "The virtue of compassion is an active regard for another's welfare, together with an awareness and empathy of the discomfort of another's suffering(1)."

"Compassion is not a virtue -- it is a commitment. It's not something we have or don't have -- it's something we choose to practice." Brene Brown

A. The Tension between Public Health and Individual Needs

An ethical principle governing restriction of visitation under the Malaysian law - Prevention and Control of Infectious Diseases Act 1988 (Act 342)(2) is the intent and moral authority to **perform the greatest good for the maximum number** to break the transmission cycle in the community. This public health law applies to community and health facilities settings. A patient with or suspect to have COVID-19 is subjected to regulations under this law, which includes quarantine and isolation. Their family may not visit a patient under confinement, even if the patient is critically or terminally ill.

The restriction of visitation is in tension with the ethical principle of **respect for autonomy and self-determination,** and disregards to a certain extent the notion **of beneficence** towards the well-being of the patient, which includes psychosocial and relational needs. Restriction of visitation is expected to be accompanied by emotional distress among patients and families. Varying interpretations of enforcement on visitation rights at individual institutions may add to this tension. Therefore, the reasons and duration for quarantine or confinement of isolation must be communicated to patients and families, and compassionate steps are in place to ensure that the mental health, psychosocial, and relational needs are met.

More than one ethical value may be relevant to a situation(3). Moral distress from presiding over one ethical principle may also bring about moral regret in healthcare workers who usually provide care according to a patient or family-centred care in a shared decision-making framework. This distress could be mitigated by having adequate information, open communication with colleagues, and knowing the compassionate steps that could be offered to patients and families during COVID-19. Here, we offer seven compassionate steps in simple language that could be undertaken during the COVID-19 pandemic by clinicians and decision-makers.

Please refer to Chapter 17 on Moral Distress.

B. Recommended Redefined Compassionate Care Steps for COVID-19

Seven Redefined Compassionate Care Steps for COVID-19 Pandemic:

1. Ensure a humane confinement environment for all.
2. Allow unique exceptions to visitations rule for young children and healthcare professionals
3. Allow photography and video conferencing as a means of family presence and communication
4. Allow other forms of (last) messages or wishes during the dying moments
5. Ensure open and effective communications at all times.
6. Avoid stigmatization of suspected or diagnosed COVID-19 patients
7. Provide palliative care for ill patients

Step 1: Ensure Humane Confinement Environment for ALL

It is critically important for the government to “ensure safe, habitable, and humane conditions of confinement, including the provision of basic necessities and, if feasible, psychosocial support for people who are confined” for COVID-19, regardless of their social background or citizenship(4) This is in line with the Universal Declaration of Human Rights (UDHR) articles 2, 5, and 25(5).

- Article 2: Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status. Furthermore, no distinction shall be made on the basis of the political, jurisdictional or international status of the country or territory to which a person belongs, whether it be independent, trust, non-self-governing or under any other limitation of sovereignty
- Article 5: No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.
- Article 25: 1. Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control. 2. Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

It is also important to ensure that additional care and support are provided, particularly to those who are particularly vulnerable, including young children, people with physical disabilities, and people who are mentally challenged. Such individuals will undoubtedly face many challenges in an environment where they may be isolated from their usual carers, and extra attention should be provided to ensure they are afforded decent care while in an isolation ward or quarantine facility. Healthcare providers should continually express empathy and compassion towards such patients who are additionally marginalised not only because of their disabilities but also because of their distress of being alone(6).

Step 2: Allow Unique Exceptions to Visitation Rule

Children

As a vulnerable group, young children with or suspected COVID-19 form a special group where a parent or caretaker's presence is required when they are being treated in the hospital environment. A just society provides special considerations for young children, who are usually in the company of their family.

The biological and emotional needs of young children for the presence of a parent or caretaker is especially heightened during an illness, especially in an intimidating environment like the hospital when their cognitive skills for proper understanding are still underdeveloped. The risk of causing emotional trauma to young children during the process of confinement and family separation may leave a long-term psychological impact(7). Even for older children and adolescents, their daily routine and social relationships will change significantly. They may not share their emotions readily, and their psychological needs may be missed.

The arrangement of a parent or caretaker to accompany children who are admitted in the hospital for or suspected COVID-19 should be made by the primary team based on infectious disease or infection control advice, with the risks communicated to the parent and documented.

Healthcare professionals

Special provisions must also be considered for healthcare frontliners whose spouse, parents, or children have been isolated for COVID-19 and in critical condition. An application to the head of infection control or hospital administrator for this purpose, citing "exceptional circumstances", should be considered. Family presence has been widely adopted by many medical societies for the reason that it helps in closure and grief of the surviving loved ones(8). The ethical arguments for allowing frontliners to have that one last moment with their loved ones include:

- Frontliners are aware of the transmission risks to themselves and the public.
- Frontliners are trained with the skills and precautions needed to keep themselves safe.
- The emotional pain and guilt of not being at the side of their loved ones while they are treating others will be insurmountable and protracted.
- The reciprocal obligations of institutions to provide mental health and psychosocial support for frontliners, especially when their loved ones are dying from the infection.

Step 3: Allow Photography and Video Conferencing

In line with redefining compassionate care in COVID and mitigating emotional distress among patients and family members, an alternative to the restriction to visitation is a mechanism to authorise a 'surrogate visit' via videoconferencing or photography for certain patients. The legal considerations under a normal condition are:

1. Personal Data Protection Act(9) and Audio and Visual Recording Guideline from MMC(10) protect a patient's right to personal privacy and confidentiality. Photography and videoconferencing may only be permitted for medical recording in diagnosis, therapy, telemedicine – and subjected to conformance with the regulations and patient consent.
2. There may be institutional policies on having photography or videos taken in the vicinity of the healthcare facilities.

Family's presence during the last moments is crucial for compassionate reasons. While dying occurs in the hospital/ICU setting, **family's presence** helps surviving loved ones to come to better closure, and to mitigate guilt and grief – through

- Involving directly in the patient's care
- Seeing that the best care has been provided, and
- Fulfilling that last wishes and accompaniment

During COVID-19, **photography and videoconferencing for the purpose of family presence and communication** between patients and their family members should be allowed, **especially when the patient is ill** (clinical Stage 3 and above for COVID-19) OR the likelihood of complications and death is increasing with following steps:

- Authorisation and protocol by MOH or hospital administration for "compassionate purposes", with clear documentation and communication with family that these photos or videos are for the circulation among family members only.
- These photos or videos should not be admitted as evidence for any legal action against the healthcare facility or its staff.

- Photography or video conferencing will be performed by staff looking after the patient, subject to clinical safety guidelines, at a time convenient to the staff and not affecting care to other patients.
- Photography or video conferencing should be performed in a manner which respects the dignity and which aims to reflect the serenity and composure of the patient

Step 4: Allow Other Forms of (Last) Messages or Wishes

If ill COVID-19 patients are still capable of expressing themselves, other forms of leaving (last) messages for their loved ones should be considered as well, with the strict condition that care will not be disrupted due to a limited workforce. "What could I do for you to make you feel better?" -- provision should be made for the (last) messages or wishes, such as

- A verbalised (and transcribed) or written message to loved ones
    - Papers could be kept in clean plastic to pass to the family
    - Transcribed messages in an electronic medium
- Living will be made with the family and legal representatives
    - Through a witnessed process by video conferencing
    - Will need approval from hospital administration

Step 5: Ensure Open and Effective Communication

During COVID-19 pandemic, effective communication **between the physician and the patient** or **physician and the surrogates (patient's family)** must be upheld as it is a benchmark of achievement of healthcare professionalism and part of physicians' duty of care towards patients -- fulfilling at least their right to information, ensuring a just and safe environment, and also to address emotional or moral distress.

The <u>SIX occasions</u> when the task of communication during COVID-19 Pandemic take place

1. Isolation and quarantine process for COVID-19 patients or suspects(11,12)
2. Breaking bad news and subsequent management plans
3. Daily updates on progress.
4. A sudden change of the patient's clinical status, of which a new update must be communicated to the patient or family at any time of the day.
5. When a revision in the goals of care and realignment of expectations are needed – to take place as early as possible(13).
6. When a request for more information by the patient or family members.

How and by whom?

Modified mediums are needed to update family given the restriction in visitation. Email or text messages to a patient's family to convey serious matters or bad news should be discouraged.

Difficult conversations: This must be held as early as possible, **by senior members of the team,** and preferably face-to-face (in person or video call). This includes family conferences.

Simple updates: This could be performed through daily phone calls around the same time (give and take 1-2 hours), by the nurse-in-charged or medical officers, with clear updates or instructions **written or prescribed by the senior member of the team** to ensure accuracy and consistency of communication.

Please refer to Chapter 15 on Communication.

Step 6: Avoid Stigmatization

COVID-19 is a global pandemic and many people are affected by it. No one should be judging or labelling people who have been infected by SARS-CoV-2 by names like "COVID19 cases" , "COVID19 infections", or "COVID19 victims". They are people who have SARS-CoV-2 infection. They are people who are being treated for SARS-CoV-2 infection(14).

Patients with suspected COVID-19 should be interviewed or counselled in a respectful manner and in an environment that ensures privacy (like a special room) and confidentiality. They should be fully informed of the subsequent procedures and management plan, and have the chance to ask questions. Their names and identifiable details should only be shared among the medical team for public health or clinical care purposes.

There is a fine line between "the need to know" to optimised care for patients and "the need to know" to warn others. Often, mental health and social impact on patients and their families when their space and dignity are breached are unseen.

Please refer to Chapter 6 on Privacy and Confidentiality.

Step 7: Provide Palliative Care

Palliative care should be considered for any patient with COVID-19 who is either ill, from the disease itself or compounded by existing co-morbids. Referral or consultation with the palliative care team can help facilitate patient and family-centred care; and assist in formulating a management plan that includes symptoms management and incorporates valued goals of care.

Please refer to Chapter 14 on Palliative Care.

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CHAPTER 17

Moral Distress And Clinician Well-Being

Sheila Gopal Krishnan, Tan Hui Siu, Chan Lee Lee

"A medical officer from the ophthalmology department was deployed to care for patients in the non-COVID yellow zone in the ED as three-quarters of ED staff had been quarantined. He has lost touch with the necessary skills such as ECG interpretation, intubation, and trauma management. He saw a 64-year-old gentleman with chest discomfort and was unsure of the ECG findings. He tried to page the medical officer from the medical department, who was busy attending to another emergency case. There was no bed in the ED to keep the patient while waiting for better assessment."

Key Points:

- Moral distress is inevitable in a pandemic situation.
- It is important to identify it and recognise the need for clinical ethics consultation.
- Multilevel strategies (personal, team, and organisational leadership) can be employed to minimise moral distress especially during the pandemic.

"Yes, if all goes well, more lives will be saved in the end without grotesque, across-the-board discrimination against the feeble or aged. And, since every life is meant to have equal worth, the more saved, the better. Nevertheless, I also cannot help feel that a crucial part of **our humanity will be chipped away** each and every time such decisions are actually made. We will not **just suffer deep emotional trauma that might scar us** for the remainder of our professional and personal lives, but also violate something basic to the calling of the healing professions. It may not be sacred, but I am not embarrassed to call it spiritual. These consequences count too."

Sadath A. Sayeed on COVID-19, 6/4/2020(1)

A. Definitions

The unprecedented stress, uncertainty, and devastating medical nature of a global infectious pandemic such as COVID-19 pandemic provide a fertile ground for moral distress (MD) among our Health Care Workers (HCWs).

1. Moral Distress (MD)

Andrew Jameton defined this in 1984(2) as a phenomenon that occurs when clinicians are unable to "do the right thing" or being helpless to prevent wrongdoing or harm. It happens when **a) institutional constraints or b) competing obligations** (Table 19) make it difficult for a person to do the right thing.

In the context of a pandemic:

- **Resource limitations -** MD is unavoidable in a pandemic situation burdened with resource limitations affecting patient care and clinician safety(3). The ethical standards of patient-centered care are different from those of public health. While clinicians are trained to make decisions based on patients' best interests, many find that it conflicts with the moral responsibility towards maximizing the public's well-being.

- **Medical uncertainties** surround the new virus. Clinicians do not know fully what works and feel despair when they juggle between the needs of the public health, patients, and themselves -- especially if there are no clear clinical and ethical guidelines to follow, or with poor leadership and suboptimal teamwork.

Table 19 Potential Institutional Constraints and Competing Obligations during COVID-19 Pandemic

A. Institutional Constraints
- Lack of preparedness/responsiveness to a pandemic: limited PPE or testing
- Lack of clinical guidelines, supervision, or mental health support
- Lack of ethical guidelines or ethics committee to resolve ethical issues in policymaking
- Workforce issues including unprepared deployment
- Ineffective team and all-levels communication including dissemination of information

B. Competing Obligations
- Concerns about the transmission of the virus from self to family and others. Unable to balance between duty of care to patient and self-responsibility to family or colleagues.
- Competing relational obligations such as parenting duties and other compulsory caregiving commitments.

Other terminology related to moral distress:

- **Moral injury,** a term originated in the military, can be defined as "the psychological distress that results from actions, or the lack of them, which violate someone's moral or ethical code(4)." The moral injury of healthcare is being unable to provide high-quality care and healing(5). Often, moral injury can also be seen as the consequence of moral distress accumulated over some time.

- **Burnout** is a "psychological syndrome as a prolonged response to chronic stressors characterized by three dimensions: emotional exhaustion, depersonalization, and lack of personal accomplishment(6)." These stressors include physical aspects like working overtime and beyond capabilities, psychological factors like a toxic working environment, or cumulative moral distress

and moral residues/moral regrets from not able to the right thing or a combination of them. There is increased emotional strain and physical exhaustion when caring for growing numbers of ill patients during COVID-19.

- **Moral residues or moral regrets** happen during a moral dilemma when a person needs to choose between two or more competing obligations or morally significant actions and left with the emotions of regrets of not doing the right thing; when in fact, there was no explicit right action in sight.

2. How is MD different from emotional or psychological distress?

MD certainly involves psychological distress; however, it is the "result of a perceived violation of one's core values and duties, concurrent with a feeling of being constrained from taking ethically appropriate action(7)." MD should be treated as a separate entity, although not mutually exclusive from psychological distress.

Psychological distress, on the other hand, describes emotional reactions to situations but does not necessarily involve a violation of core values and duties. Some of the emotional or psychological distress arising from COVID-19 include:

- The anxiety when assuming new or unfamiliar clinical roles or increased workloads
- The sense of despair, grief, and fear from witnessing the relentless and unprecedented scale of human suffering progressing rapidly during COVID-19, reinforced by simultaneous reports globally through the media.
- Fear of potential lawsuits or criminal charges or being isolated or quarantined.

B. Recommended Eight Solutions to Moral Distress

Eight Solutions to Moral Distress during COVID-19

1. Identifying any evaluative error or error in moral judgement
2. Keeping up to date with the latest information
3. Clarifying roles and responsibility
4. Anticipating and building capacity for new skills and competencies
5. Calling for ethics consultation and support.
6. Building personal resilience through decompression and activation
7. Ensuring personal well-being
8. Seeking mental health support if needed

Solution 1: Identifying any evaluative error or error in moral judgement

Evaluative error happens in MD. Inaccurate perception or lack of information causes a person to assume that she was unable to do the right thing(8). Three possible types of errors:

- Being new to the institution, a person may not know of the support available or the capacity of the system to help her provide the best care for her patients.
- She may not be aware of the latest medical evidence in the clinical management of the disease.
- Intrinsic understanding of morality itself may have caused a person wrongly judging that an act is not right.

Evaluative error is different from moral or cultural (societal/organizational) relativism – that is, different values or belief systems. Therefore, a broader range of expression of MD must be encouraged with a non-intimidating and non-retributive avenue to assess the validity of MD and to seek resolutions. This includes reporting to the supervisor or a referral to ethics consultation.

Solution 2: Keeping up to date with the latest information

In a pandemic, lack of information and misperceiving institutional constraints, competing obligations, and the latest medical evidence may cause MD. Clinicians must keep themselves abreast of the latest medical knowledge and protocols for the correct sources. As a team member, clinicians have to follow institutional pandemic protocols, which include roles and responsibilities, clinical management, and decision-making processes. Clinicians need regular and transparent updates from their institutions to know what is expected, the safety risks, and the protection or support available during a pandemic.

Solution 3: Clarifying roles and responsibility

Clinicians need to clarify their roles and responsibilities by having open communication with managers and the team at all times. Clinicians need to admit to their strengths and limitations and knowing when and how to seek the necessary support. This includes new job descriptions and deployment to other areas.

Solution 4: Anticipating and building capacity for new skills and competencies

Early preparation and training for new skills and competencies (clinical procedures, management, or decision-making) help clinicians to be confident. It is the duty and moral obligations of clinicians to perform at their highest level of skills and competencies during a pandemic.

Solution 5: Calling for ethics consultation and support

MD could be the first sign of a moral dilemma. A clear ethical guideline that addresses potential ethical issues in terms of clinical care and decision-making help reduce the situation of a moral dilemma and MD. In a less urgent scenario, an institutional/clinical ethics committee or support could be called to assess and resolve ethical dilemma or conflict, and to review any institutional policies that give rise to MD.

Please refer to Chapter 11 on the Role of Institutional Ethics Services

Solution 6: Building personal resilience through decompression and activation

Burnout could be the consequence of cumulative MD but could also arise from physical and psychological stressors. Institutions could look into assessing for the presence of personal resilience(9) (Table 19) that buffers burnout among clinicians and to work on measures to improve the well-being of clinicians(10).

Table 20 Press Ganey 8-item assessment tool for the presence of personal resilience

Activation	Decompression
1. I care for all patients equally when it is difficult 2. I see every patient as an individual with specific needs 3. The work I do makes a real difference 4. My work is meaningful	1. I can enjoy my personal time without focusing on work matters 2. I rarely lose sleep over work issues 3. I am able to free my mind from work when I am away from it 4. I am able to disconnect from work communications during my free time

Solution 7: Ensuring personal well-being

Several steps to "self-care":

- **Meeting basic needs:** Attend to spiritual and bodily needs such as healthy food, water, basic exercise, and rest. Refrain from substance abuse.
- **Relaxation/decompression activities:** These include deep breathing exercises, meditation, sensory relaxation, reading, and art expression.
- **Social support:** Lockdown imposes unwanted separation from families and friends. Clinicians need to use innovative technologies to keep in touch and maintain their own social network as part of mental health well-being.
- **Self-awareness and mindfulness of warning signs**: burnout, despair, depression, and unresolved anger. Explore existing MOH pathways to combat unresolved stress such as Mental Health & Psychosocial Support Services (MHPSS) and Psychological First Aid (PFA)(11) (Appendix 9)

Solution 8: Seeking mental health support if needed

Clinicians need to be supported when they face mental health issues. These include having open discussions with colleagues and keeping tab of each other emotions and using measures like the PFA without stigma and to comply with treatment sessions.

- PFA is a supportive response to a fellow human being who is suffering and may need support. **Prepare** and learn about available services and support. **Look** and check for people with serious distress reactions**. Listen** to people's needs and concerns. **Link** and connect people with loved ones and social support.

Table 21 Recommended Eight Solutions to Moral Distress during Pandemic

Moral Domains	Mental Health/Psychosocial Domains
Identification of an evaluative error - Lack of knowledge - Medical uncertainties - Intrinsic understanding of morality	**Building personal resilience from burnout** - Decompression - Activation
Keeping up to date with information - Evidence-based medicine - Institutional protocols on roles and responsibilities, clinical management, and decision-making process - Transparent pandemic updates - Available protection and support	**Ensuring personal well-being or "self-care"** - Basic needs - Relaxation and decompression techniques - Social support - Self-awareness and mindfulness of warning signs
Clarifying roles and responsibilities - Open communication with team - Be aware of strengths and limitations	**Seeking mental health support if needed** - Open discussions, PFA/other screening - Attend treatment sessions
Anticipating and building capacity for new skills and competencies - Duty and moral obligation to patients and society - Early preparation and training - Clinical procedures, management, decision-making	
Calling for ethics consultation and support - Ethical guidelines - Clinical ethics committee (CEC)	
Team managers & healthcare leaders to ensure that ALL of the above is met	

The Roles of Team Leader or Manager in a Healthcare Facility in Moral Distress (adapted from WHO Mental Health and Psychosocial Considerations during the COVID-19 Outbreak)(12)

- **Pre-arrangement of daily living support** such as childcare support or alternative living arrangements for clinicians could help to reduce stress on the responsibility to family while minimizing the risk of viral spread to families.
- **Ensure good quality communication and accurate information updates.**
- **Sharing moral responsibility** by encouraging a team-based approach to decision making from the start of care to shoulder ethically challenging decisions. A pre-planned and well-structured triage protocol is useful for allocating scarce resources.
- **Distributing workload** by proactively involving an ethics team or palliative care team and offset emotionally difficult task of communicating with families on treatment plans and prognosis.
- **Working in a consistent team** that rotates to foster peer support and morale.
- **Time and space to decompress** by having a dedicated place for staff to rest and ensuring staff has enough time to recover between shifts.
- **Being supportive.** Floor supervisors could regularly walk through the unit to provide real-time support, identify immediate staff needs, remind staff to monitor themselves for stress reactions, facilitate handoffs when a break is needed, and even lead quick "huddles" or debriefing sessions after a stressful event or procedure to provide social support.
- **Facilitate or make aware of mental health and psychosocial support services** to all staff.

The Roles of Healthcare Leaders in Moral Distress(3,13)

Healthcare leaders should support the well-being of clinicians, who are working under unprecedented stress; and to recognize the solutions to moral distress. Three areas of governance are:

1. **Planning for the uncertainty ahead:** Most healthcare systems do not anticipate the magnitude of the disruptions of COVID-19. A structured approach in facilitating clinicians to do their job is much needed. Healthcare facilities should have:

- Clear policies regarding the decision-making process and management of patients.
- Designated professionals within the system to lead different areas.
- Open communication with clinicians to avoid misinformation or evaluative errors.
- Consideration for staff welfare -- physical, mental health, and psychosocial needs, including the provision of emergency childcare.
- Mechanism to evaluate the presence and factors of personal resilience among clinicians.
- Services such as MHPSS with information well disseminated.
- Systematic deployment and roster planning to ensure clinicians could perform at their highest level of competencies and skills with adequate time for rest.
- Clear surge capacity plan, like increasing the availability of existing beds and equipment.
- Engagement with the ethics committee to resolve conflicts or dilemmas for cases or organization.

2. **Safeguarding:** Coordinated efforts to prevent infection among clinicians must first be made through safe practices and reminders on social distancing, hand hygiene, and appropriate usage of PPE. It is the duty and reciprocal obligation of healthcare leaders to protect them as they risk themselves in the course of tending to patients. It is also a public health imperative that the prevention of healthcare-associated infections must be in place. Healthcare facilities must have:

- Transparent policies and adequate supply of different levels of PPE for HCPs at all times.
- Evidence-based approach with lower threshold of protection given the medical uncertainties.
- Adequate training for new skills/competencies e.g. donning and doffing of PPE and resuscitation.
- Arrangements for alternative accommodation for staff who are quarantined to relieve the psychological stress of transmitting the virus to their family and colleagues.

3. **Lead & Guide contingency level of care and crisis:** Conduct risk assessments: identify critical operations, identify threats to those operations and to analyze the potential impact such as exposure of clinicians to COVID-19 in the ED through scenarios, trigger activation, response overview, safety monitoring and report, key person, timeline to audit.

Please refer to Chapter 2 on Clinical Governance.

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CHAPTER 18

Ethical Standards And Their Application To Research During Public Health Emergencies

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"In Country X, while the research initiatives received tremendous fund, healthcare officials has been informing the people that given the absence of effective pharmaceutical intervention, unproven anti-malaria (hydroxychloroquine) drug would be best at treating the condition. All COVID-19 patients were immediately prescribed with the drug along with azithromycin outside of a controlled setting. The risk of death was recorded higher among these groups of patients. Desperate patients, including healthcare workers, were self-medicating by taking the drug or its derivatives. They developed side effects and even ended up dying."

Key points:

- Research in the context of pandemic require cautions interpretation unlike during non-pandemic times.
- Regular review process no longer applies during a pandemic. It should be based on key ethical standards that provide guidance during a public health emergency.
- Designing research study and recruitment of patients during a global crisis need to be reasonable and safe.
- Sharing of research data must be considered carefully and adhere to ethical requirements maintaining confidentiality and privacy of information

A. Introduction

In responding to the COVID-19 pandemic, several guidelines published in the past can be used to provide guidance on the ethical conduct of research during public health emergencies. These guidelines were drawn up as responses to the following outbreaks: Severe Acute Respiratory Syndrome (SARS) (2003), influenza A (H1N1) (2009) and the Ebola virus disease (EVD) (2014-2015). The current guidance issued by the WHO[5] is also a useful reference.

This section outlines some key ethical standards that should be considered by researchers, review bodies, and sponsors when conducting research relating to COVID-19.

During a pandemic or a public health emergency such as COVID-19, there is a moral obligation to conduct research to explore the uncertainties, help in the effort to find a cure and work towards prevention and control of the current disease or future strains.

However, it is essential that proper oversight mechanisms are put into place to ensure adequate scientific evaluation of any proposed research. This will ensure that the impact of new findings will hopefully benefit the public health response around the world and prepare for future outbreaks[1,2].

The moral obligation to conduct research also necessitates that it is designed carefully and adheres to ethical principles[10] to protecting the dignity, rights and welfare of research participants. Along with the clinical trials (assessing & evaluating diagnostics, treatments, or preventive measures like vaccines) research of other kinds (i.e. social science/epidemiological/behavioural/implementation/etc) can be beneficial in decreasing the morbidity and mortality and deal with the social and economic effects due to the outbreak[1].

Additionally, research should only be conducted if it does not impede emergency response efforts[3]. It should never compromise public health responses or clinical care but should be designed and implemented to work with other public health interventions. In Malaysia, "All clinical trials must be prospectively registered in an appropriate clinical trial registry" for example the National Medical Research Registry (NMRR) and undergo ethics review by the appropriate committee such as the National Institute of Health (NIH) Medical Research Ethics Committee (MREC).[1]

There are seven (7) requirements proposed by Emanuel, Wendler & Grady (2000)[3] to make clinical research ethical that integrates protection and basic philosophy all major guidelines on the ethics of biomedical research with human participants:

1) *scientific and social value*
2) *scientific validity*
3) *fair participant selection*
4) *favourable risk-benefit ratio*
5) *adequate independent review*
6) *informed consent*
7) *respect for potential and enrolled participant*

(from Emanuel, Wendler & Grady (2000))

B. Research and Ethics in Relation to the COVID-19 Pandemic[1,4,5,6,7]

1. Local researchers/research institutes:

- Available local research institutes should be involved in designing, implementing, analysing and reporting outbreak-related research that responds to local realities/context to ensure effective implementation without compromising ongoing emergency response activities.
- Local researchers should be involved in international research collaborations that contribute to long-term research capacity building of affected countries in a manner that promotes the value of equity.

1) [10] There are seven (7) requirements proposed by Emanuel, Wendler & Grady (2000)[3] to make clinical research ethical that integrates protection and basic philosophy all major guidelines on the ethics of biomedical research with human participants: 1) scientific and social value, 2)scientific validity, 3)fair participant selection, 4)favourable risk-benefit ratio, 5(adequate independent review , 6)informed consent, 7)respect for potential and enrolled participant .

2. **Addressing limitations in local research ethics review & scientific capacity**[1,2,6]:
   - In a pandemic, the regular review process for a research in a clinical setting (i.e. design of the study, the study timeline, participant recruitment, assessment of risk and benefit, and sharing of evidence) is compromised dealing with the global emergency. Unlike the routine review period that is appropriate for a much slower-paced study, it is crucial to note that all the said factors are no longer the same in a pandemic/emergency crisis using an adaptive trial. The process is sped-up, reviews are accelerated, adequate risk and benefit are complicated and challenging to asses, and the design of the study including the recruitment process altered to fit the global/national emergency. These review committee may have difficulty in assessing these factors.
   - "Countries' capacity to engage in local research ethics review may be limited during outbreaks because of time constraints, lack of expertise, diversion of resources to outbreak response efforts, or pressure from public health authorities that undermine reviewers' independence. International and nongovernmental organizations should assist local research ethics committees to overcome these challenges by, for example, sponsoring collaborative reviews involving representatives from multiple countries supplemented by external experts"[1].
   - Sponsors and funders are responsible to set standards and encourage data sharing for the trials that they fund. To ensure responsible conduct, they need to work closely with multiple key stakeholders such as the regulatory agencies (i.e. MREC, NIH), the investigators, the study participants, and the research laboratories & universities implementing transparency.

3. **Accelerated Ethics review during the outbreak**[1,5,6]**:**
   - Ethics committees (institutional/national) need to recognise the need to provide immediate action considering the outbreak and if accelerated pathways are not available, devise mechanisms to accelerate the review process.
   - An option would be to authorize an advance review of generic protocols for research during outbreak conditions and adapt rapidly to specific protocols.

4. **Joining forces (outbreak research)**[1,2,4]**:**
   - Country based national authorities can work with international organization such as the World Health Organization (WHO) to develop projects with set priorities that allow for a broader response effort.
   - In such instatnces, there is an obligation to share information (i.e. confidential information, hidden case, transmission chains, resistance to response measures, etc) and as such, there is a duty to inform participants of the possibility of their information being shared with research partners.

5. **Equitable sharing of resources:**
   - Any outbreak related research should not be done if it takes away excessive resources and personnel, equipment or healthcare facilities from clinical and public health efforts.
   - The national government and health agencies should evaluate the available resources (i.e. funds, health related equipment, facilities and clinical experts) and strategize to effectively utilize for both public health related efforts and clinical studies, although the former is of priority.

6. Managing fear/worry among researchers/members of ethics committees[6]:

- The committee members are to participate in an impartial assessment of risks & benefits of research participants.
- Those involved in approving research protocols during a pandemic, need to ensure clinical trials are only initiated when there is a reasonable scientific basis and the experimental intervention is safe & efficacious with minimized risks which is different from the regular review process which is not time sensitive or conducted in an state of global/national emergency.
- To manage therapeutic misconception (i.e. misconception that the clinical trial/intervention is designed mainly to directly benefit the participants instead of developing information for the potential benefit of people in the future).

7. Managing barriers to informed consent[1,5]:

- All prospective participants need to be able to weigh the risks and benefits of participation in the research. In the instance of severe manifestation of the disease and with some participants confined to intensive care unit (ICU), a legal representative (i.e. spouse, parents and legal guardian) should be included in the informed consent process.
- Other factors that challenge researchers from obtaining informed consent:
    - High level of distress among patients and families
    - Communication between healthcare workers and patients/families due to high distress is challenging
    - Cultural & linguistic differences (local and migrant populations)
    - Potential participants that are placed in quarantine or isolation and are cut off from families and support
    - Incapable of refusing participation in research
- Consent needs to be compatible with the international research ethics guideline (For example, the 2016 International ethical guidelines for health-related research involving humans by 'The Council for International Organizations of Medical Sciences (CIOMS)', Declaration of Helsinki, etc) & developed with the help of local communities (i.e. that are familiar with the social and cultural concerns) & implemented by locally recruited personnel (i.e. as members of the national healthcare agencies).

8. To gain and maintain trust[1] of participants:

- Any failure will delay recruitment and completion
- Undermine the approval of any intervention as efficacious.
- "Engage with affected communities before, during and after a study is essential to build and maintain trust"[1]

9. Rapid data sharing[7]:

- Sharing research information subject to ethical requirements (maintain confidentiality & privacy of information with those participating in response effort to strike a beneficial balance.
- Researchers, journals and sponsors are recommended to share their research findings and data pertaining to the pandemic rapidly and openly to inform the public health response

10. Ensure equitable access to the benefits of research which includes future vaccine

- Sponsors, pharmaceutical manufacturers and governments are recommended to provide equitable access at a global level for all new vaccines, diagnostics and treatment for COVID-19[8].
- The distributive justice principle found in the CIOM'S Eighth Guideline for international research on human subjects would be a good guide on the topic of fair access.
- There should be consensus established on what considered as essential in order to satisfy individual and collective wellbeing, as well as the parameters involved in the legitimacy of these distributive criteria and the resolution of ethical conflicts during the allocation of drugs, vaccines, treatment and others.

C. Ethical Issues Arising From Using Investigational Drugs During Pandemic

1. Investigational drugs by definition are substances approved by the local drug authorities for testing in people. Although approved for use in one disease/condition, a drug can still be considered as an investigational drug when used in other diseases/conditions and is known as an investigational experimental drug (IND), investigational agent or investigational new drug.[9]

2. According to WHO, at the present time, no pharmaceutical products (i.e. drugs/vaccine) have proven to be neither safe or effective in treating Covid-19. However, a few drugs/medicines have been indicated as potential investigational therapies (can refer to Clinical Trials) which are either being used or will be used in upcoming clinical trials.[10]

3. The registration of all clinical trials in appropriate registries is necessary to ensure that decisions about healthcare are informed by all available evidence. Informed decisions are made when there is no publication bias or selective reporting. “Every clinical trial must be registered in publicly accessible database before recruitment of the first subject” (Declaration of Helsinki; §34).

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4. Globally, doctors are reported to be offering drugs/medicines to Covid19 patients that have not been specifically approved for this disease.
   “*The use of licensed medicines for indications that have not been approved by a national medicines regulatory authority is considered “off-label” use. The prescription of medicines for off-label use by doctors may be subject to national laws and regulations. All health care workers should be aware of and comply with the laws and regulations governing their practice. Further, such prescribing should be done on a case-by-case basis. Unnecessary stockpiling and the creation of shortages of approved medicines that are required to treat other diseases should be avoided*” (*from World Health Organization, 2020*).[4]

5. Off-label use of drugs to treat COVID-19 are not advised as it is risky and dangerous. Although, globally there are doctors providing their patients with experimental drugs/medicine/intervention as last resort, the outcome is still uncertain. For example, if a patient dies after being prescribed of that drug, the interpretation is he/she died of the disease but if the patient survives it is because of the drug. This interpretation is false. In the absence of a control group, it is

impossible to distinguish between the adverse effect brought using the drug and the manifestation of the disease alone.[11,12] It should only be done as clinical trial to gather evidence in a controlled group.

6. Any decision to offer a patient an experimental/unproven treatment is between the doctor & the patient but must adhere to the national law/policy. This type of treatment when/if possible, should only be given as a part of clinical trial unless a patient decline to participate. But if clinical trial is not possible, then the treatment & its outcome should be recorded following national law/policy. [5,6]

7. If the experimental or unproven treatment show promise based on its initial results, the treatments should be studied further in the form of clinical trial to assess "efficacy, risks and benefits".[5,6]

8. Previous World Health Organization (WHO) guidance by the Ebola Ethics Working Group suggested the term "monitored emergency use of unregistered and experimental interventions (MEURI)".[1,6]

9. **Ethical justification for MEURI:**
   - The principle of respect for patients' autonomy. That any individual has the right to make "*their own risk–benefit assessments" judging by "their personal values, goals and health conditions" (from World Health Organization, 2014*)[1]
   - It is also upheld by the principle of beneficence so long as the patients are given reasonable opportunities to improve their condition and steps are taken to probably ease the emergency and extreme[1]

10. **Scientific justification for MEURI:**
    - "*Countries should not authorize MEURI unless it has first been recommended by an appropriately qualified scientific advisory committee especially established for this purpose. This committee should base its recommendations on a rigorous review of all data available from laboratory, animal and human studies of the intervention to assess the risk–benefit of MEURI in the context of the risks for patients who do not receive MEURI*" - *from World Health Organization, 2014)* [1]

11. **MEURI should be guided** by the same ethical principles that guide use of unproven compounds in clinical trials, including the following:
    a. Significance of ethical oversight
    b. Effective resources allocation
    c. Minimizing risks
    d. Collection & sharing of meaningful data
    e. Importance of informed consent
    f. Need for community engagement
    g. Fair distribution in the face of scarcity

C. Community Engagement: Sharing Research & Response[6]

1. The pandemic/outbreak response efforts ought to be supported by early and ongoing engagement with the affected population and community worldwide.
2. Community engagement is important ethically and considered crucial in maintaining trust and preserving social order.
3. Involving the communities in the planning and response efforts during a pandemic or outbreak (including the many stages) require focus on the following:

- **Inclusiveness**
    - everyone has equal opportunity to be heard in all stages (directly or through legal representation)
    - enough communication platforms and tools need to be in place to help with public communication with the healthcare authorities.

- **Situations of vulnerability**
    - people facing heightened susceptibility (i.e. elderly, people with underlying medical conditions, children, pregnant women, living in red-zoned area, and others) to injustice/harm during the pandemic and outbreak should be:
        - given special attention so that they can still contribute to decisions on the planning & response towards the disease.
        - healthcare authorities need to identify them (and others that distrust the government & other institution) and place effort to include them in community engagement plans
    - When groups of people have difficulty in accessing services & resources there is a need for effective communication strategies (i.e. communication barrier & illiteracy, etc), stigmatization & discrimination, disproportionate burdens and heightening risk of violence (bring about social conflicts, increase criminal acts upon vulnerable people like refugee or migrants, etc).

- **Openness to diversity**
    - All efforts of communication at the moment are designed to enable a 1-way dialogue instead of one-way decision announcement of decisions already made. For example, currently the press conferences are only to relay information and decisions by the healthcare agencies. But including members of the community prior to these decisions should be considered to get the relevant feedback from the people for that decision making. Such inclusivity would gain trust among people and feel heard.
    - Involving the community, the information received & gathered would be thorough and open. Decision makers would then recognize & prepare alternative approached and review the decisions when/if needed.
    - Therefore, it is important to reach the community early and distinguish the interests of people that can be potentially affected so that they can play a role in building the trust and empower them

- **Transparency**
  - The healthcare authority/decision makers ought to publicly explain the rationale of their decisions (using language that is linguistically and culturally appropriate)
  - When making decisions with uncertain information, it is important to be explicit about the uncertainty and convey this to the public.

- **Accountability**
  - People need to know who is responsible for making and implementing the decisions pertaining to the pandemic or outbreak response and how they can contest the decisions that they consider inappropriate.

Table 21 Ethical Justifications For Or Against Accelerating The Process Of Developing And Approving These Drugs/Vaccines

Ethical	Un-Ethical
- Compassionate use of IND - That there is no other treatment available proven to treat the deteriorating COVID-19 patients - Therefore, it is acceptable to treat with available drug since not enough time to conduct research to gather information on the risks and efficacy of the drugs.	- The use of the IND that are tested for other disease (or even FDA approved) for COVID-19 is risky. The effect may be inconsistent and does not factor in underlying conditions or the population such as elderly, vulnerable (pregnant women & children), etc. - For example: hydroxychloroquine & azithromycin that is approved for lupus, arthritis and Malaria but may be have serious implications for people with existing cardiovascular disease (including those yet to diagnose with cardiovascular conditions) (Roden, Harrington, Poppas & Russo, 2020) - Remdesivir is another drug that is being used to treat COVID-19 patient. There is a report that out 53 patients, 36 improved clinically. - But mild to moderate liver function abnormalities were noted as a side effect in the new Remdesivir research. 12patients, had serious side effects including multiple-organ-dysfunction syndrome, septic shock and acute kidney injury. - "we found that lopinavir–ritonavir treatment did not significantly accelerate clinical improvement"[14]

- Healthcare and public health authorities need to have a proper channel and prevent giving out false hope and information that can lead to misconception. - Transparency is crucial	- False hope & misconception due to many baseless authorization - Trump's strong perception on hydroxychloroquine which is against by his COVID-19 advisors and making wild announcement over the news/social media. - Some patients taking the wrong drug listening to Trump just because they think the compound are similar resulting in death.
The need to have a mechanism to expedite approval from ethics committee and/or FDA for a proper clinical trial to ensure there are possible option for treatment for all patients.	RCT with placebo design would be un-ethical in a pandemic situation with high mortality

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Gopalan N., Yusof A. N. M., Cheah P.Y. & Kaur S. (2020). Ethical Standards and Their Application to Research during Public Health Emergencies. In Tan H. S. & Tan M. K. M. (Eds.), *Bioethics and COVID-19: Guidance for Clinicians* (1st Ed.) (pp. 103-112). Malaysian Bioethics Community.

CHAPTER 19

Towards An Ethical Response To COVID-19 In Malaysia

The following statement was published on 20th March 2020 and is reproduced in its entirety with permission as below:

We are a group of Malaysians involved in bioethics and medicine and have been following the progress of the COVID- 19 pandemic globally and locally. Public health officers and healthcare providers are on the frontlines of this ever- changing situation, where they have to adapt daily to allocate resources, mobilise the workforce, and coordinate services. Current public health measures, including the Movement Control Order, should be applauded but it is becoming increasingly clear that the system is going to be overwhelmed in the near future. It is inevitable that whilst traversing these unchartered territories, ethical issues will arise. These mainly arise in two specific contexts. Firstly, in managing the tensions between public health interests and individual interests; and secondly, in ensuring trust and trustworthiness. We believe that there is a need to address these and other critical ethical issues that will arise.

1. MANAGING TENSIONS BETWEEN PUBLIC HEALTH INTERESTS AND INDIVIDUAL INTERESTS

Situations such as the COVID-19 pandemic create considerable tensions between public health interests and individual interests. When designing policies and interventions that maximise common good (public health interests), it is vital to keep in mind the need for approaches and methods that minimise harm to individual interests, particularly the interests of vulnerable populations.

While restrictions on the rights and freedom of individuals are scientifically and ethically required to contain the spread of infectious diseases, measures must be put into place that ensure people are treated with dignity and that certain populations such as the elderly, the poor, the disabled, students and migrant workers do not bear a disproportionate burden of the risk. Hence, responses should be guided by the following ethical principles:

I Justice

- Promoting equity - fair distribution of benefits and risks, including limited clinical resources such as ICU beds and other medical equipment.
- Procedural justice - there should be a fair and clear decision-making process and affected stakeholders should be provided with opportunities to be heard.

II Respect for persons

- Treating individuals with dignity and more importantly in this context, providing safeguards for persons with particular vulnerabilities.
- Maintaining confidentiality of patients being treated by all parties, including civil society and individuals.

2. ENSURING TRUST AND TRUSTWORTHINESS

Ultimately, the success of any measure or intervention will depend on all stakeholders acting in concert with a sense of shared responsibility to coordinate responses. Decision makers must ensure that trust is not lost and that systems are trustworthy. This should include:

I **Transparency and accountability**

- Open communication is key and effective alternative communication strategies should be explored to ensure that vulnerable populations such as the elderly, disabled, and migrant workers are able to access accurate and up to date information.
- Lines of responsibility and accountability should be clear and transparent.
- Those seeking treatment for any kind of ailment should be upfront with healthcare workers about their history of contact with suspected or confirmed COVID-19 patients.

II **Good governance**

- Processes that promote efficiency, effectiveness and ethical decision making should be put into place.
- All key stakeholders regardless of political, religious or community affiliations should be included.
- Adequate support for frontline workers by providing safe work environments, adequate accommodation arrangements for those who need to be mobilised and assistance for family members and moral support.

We hope that the points emphasised in this statement will enhance ethical thought processes, thus leading to thoughtful deliberation and decision-making during this difficult period of time. Each of us will continue to work with all stakeholders in ensuring that the Malaysian response to COVID-19 will be a success.

This chapter can be cited as:
Malaysian Bioethics Community. (2020). Towards an Ethical response to COVID-19 in Malaysia. In Tan H. S. & Tan M. K. M. (Eds.), *Bioethics and COVID-19: Guidance for Clinicians* (1st Ed.) (pp. 113-114). Malaysian Bioethics Community. DOI: 10.5281/zenodo.3819872.

CHAPTER 20

Ethical And Responsible Journalism Resulting In Impactful Engagement With Refugee/Migrant Populations During The COVID-19 Pandemic

The following statement was published on 23rd March 2020 and is reproduced in its entirety with permission as below:

In advocating for ethical and responsible journalism when engaging with refugee/migrant populations during this pandemic, here are some ethical principles to reflect:

Solidarity

- Both parties have a common interest and objective and hence, should be united in supporting measures to achieve this goal. However, contributing to achieving this common goal will also depend on our individual situations.
- Acting in the common interest may mean that parties may have to make some sacrifices in order to achieve the goal. For example, articles that are less sensational may not be circulated as widely or as quickly.
- It is important to remember that every person has a role to play.
- While journalists may be working under pressure (and this is understandably so as these are challenging times), it is good to keep in mind certain ethical principles. It may be be useful to consider the following questions in relation to your sphere of influence and action:
    - *What is my role in this specific situation? How can I be a part of the solution?*
- For journalists, the answer to these questions should reflect the unique position and skills you have, which you can contribute to this effort.

Embracing the spirit of solidarity, the next ethical principle to keep in mind would be:

Respecting persons and treating them with dignity

- It is important to be mindful that each and every person deserves to be treated with dignity.
- Unfortunately, certain groups of people are typically not treated with dignity and have little or no influence to challenge their situations.
- In the best of circumstances, refugees are discriminated against socially, economically marginalised and lack any long-term security.
- This is significantly compounded by the COVID-19 situation where they will be faced with even more stigmatisation and discrimination.
- Treating them with dignity requires everyone to recognise and mitigate these risks.
- As a society, we owe it to them in the spirit of solidarity so that **they** can play their part without fear of social or governmental reprisals.

If language and communication skills are your armoury, use them to the best effect. Endeavour to foster the spirit of solidarity, be mindful of harming it. The WHO and a number of UN agencies have developed helpful and practical tools that can be usedto promote responsible journalism[1]. Referring to them is a good step in the right direction.

[1] World Health Organisation, 2020. A guide to preventing and addressing social stigma. Available from: https://www.who.int/docs/default-source/coronaviruse/covid19-stigma-guide.pdf.

This chapter can be cited as:
Malaysian Bioethics Community. (2020). Ethical and responsible Journalism Resulting in Impactful Engagement with Refugee/Migrant Populations during the COVID-19 Pandemic. In Tan H. S. & Tan M. K. M. (Eds.), *Bioethics and COVID-19: Guidance for Clinicians* (1st Ed.) (pp. 115-116). Malaysian Bioethics Community. DOI: 10.5281/zenodo.3819971.

CHAPTER 21

Responses To Ethical Guidelines

Tan Hui Siu

Rightly pointed out by a good friend recently, the responses from clinicians and leaders to the needs of ethical guidelines for COVID-19 may be summed up by Maxwell Smith and Ross Upshur's writing in "Pandemic Disease, Public Health, and Ethics(1)." Their opinion on the functionality of ethical guidelines during a pandemic were:

- *"As noted in response to the 2014-2016 Ebola Virus Disease outbreak, a failure remains for these guidance documents to be assessed and used in a timely fashion that informs and shapes responses to pandemics.*

- *"Part of this failure may be explained by the fact that the (ethics) guidance documents largely exist as *stand-alone documents* and are not typically integrated into operational pandemic plans.*

- *"Another part of this failure may be explained by the lack of attention to ethics education in medical and public health training programs.*

- *"Yet another element may be the unfamiliarity with the type of reasoning required for ethical reflection and deliberation.*

In Malaysia, the initial hurdles during the development of a COVID-19 ethical guidance include the lack of a unified bioethics group or taskforce in Malaysia, the absence of any established clinical ethics committee or platform, and the lack of awareness among clinical leaders on the roles of bioethics. The platforms related to professional ethics, research ethics, ethics related to biotechnology could be found in the ministry, academia, and the medical council in Malaysia. However, clinical ethics has been an unfamiliar field to many in Malaysia, along with other subfields of bioethics like public health ethics, feminist ethics, and narrative ethics.

The pressing need to form a united bioethics community in Malaysia was felt acutely during the COVID-19 pandemic crisis as ethical issues were observed by individual ethics groups. Heated debates roamed around in the paediatric bioethics and the research ethics groups. Generally, there was a shared contention among many clinicians and healthcare leaders in Malaysia that we have been successful in keeping the pandemic curve relatively flat, and there was no dire need for any ethical guidelines or triaging protocols. Nevertheless, the requests from several Malaysian clinicians on the ground for an ethical guideline could not be ignored:

- *"Do you have a written guide for ethics specifically design for Malaysia circumstances in faction this catastrophic COVID-19? If you have one, kindly share it with me. As you understand, Malaysian are unique for our diversity, economic circumstances, etc. Hence clear guidance is of the utmost importance. We don't want a bias, misleading, nor misinterpretation of doctor's deacons. And hopefully, none will manipulate it that can spark any hate and disharmony of the system."*

- *"Professional ethics? No avenues within the system for HCW to express distress."*

- *"Very important for us to have similar guidance and protection for frontliners doing emergency COVID work in Malaysia. Adult ICUs are disposing of their ICU charts on discharge. Thinking of asking the ministry to issue some statement or guidance protecting us over here. Desperate times, don't want some lawyer picking over why I didn't document a 3 am emergency phone call more thoroughly after this mess is over."*

- *"Yes, in our hospital, they don't have a functional computer charting system in the COVID ICU. All ICU charts will need to be disposed of due to contamination. I suggested that he snapshot key documents and digitally record or print a copy."*

- *"Family members of patients near death should be granted compassionate use of personal protective equipment if possible so that they can be with the dying patient. If this is not possible, hospitals should help families use videoconferencing technology to hold bedside vigils at a distance. Health care workers will also need emotional support."*

Through these engagement done with the clinicians and health care leaders in February and March 2020, when Malaysia met with her 1st and 2nd wave of a drastic spike of cases, it was decided by this editor that the lengthy philosophical writing of the "Bioethics Guidance for COVID-19 Malaysia" that was circulated on the 20th of March 2020 did not meet the expectations and needs of local clinicians, and should be replaced with specific recommendations and a more straightforward guide.

Malaysian Bioethics Community was formed on the 28th March 2020 and one of the responses that they made was to set up and online clinical ethics consultation and also to complete the near-impossible task of developing a comprehensive ethical guide in a short span of 6 weeks. Over 30 persons with a diverse group of bioethics background -- physicians, medicolegal lecturers, lawyers, and researchers worked against time to release it to support clinicians, patients, and families in May 2020.

This ethical guide aims to be clinical ethics-focused and specific to the Malaysian context. The thoughtful deliberations in small and large groups were heartening and amazing. The unified act of these Malaysians during the COVID-19 crisis despite how diverse and stranger they are to each other, and the original ideas and respectful process that went into the development of this guideline -- should be a force to be reckoned with. That itself is a great milestone in the journey of bioethics in Malaysia.

Reference

"Pandemic Disease, Public Health, and Ethics" by Maxwell Smith and Ross Upshur, from the Oxford Handbook of Public Health Ethics, September DOI: 10.1093/oxfordhb/9780190245191.013.69.

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Tan H. S. (2020). Responses to Ethical Guidelines. In Tan H. S. & Tan M. K. M. (Eds.), *Bioethics and COVID-19: Guidance for Clinicians* (1st Ed.) (pp. 117-119). Malaysian Bioethics Community.

AFTERWORD

The Origins Of The Malaysian Bioethics Community (MBC)

Mark Tan Kiak Min

"When you walk through the storm hold your head up high… at the end of the storm is a golden sky…"

Over the past couple of years, Sharon and I have had the providence of meeting many of the individuals who are involved in the Malaysian Bioethics Community (MBC), either individually or collaboratively. As a result of this, we realized that there were many others involved in or interested in the field of bioethics in Malaysia. However, due to the relatively large scope that bioethics covers and the variety of people who are involved in it, we must have been working individually with the same passion for the subject.

In late 2019, we met HS (who had just returned to Malaysia) for the first time at the UM Faculty of Law. As a result of that meeting, we had planned to collaborate in organizing an ethics conference in 2020. We sent out invitation to some collaborators, and together, started to embark on an adventure into the unchartered waters of bioethics in Malaysia.

Unfortunately (or fortunately I should say), the storm created by the COVID-19 pandemic emerged then happened, and the Movement Control Order was announced by the government. We had by then realized that something serious was happening in the world, one that would involve many unprecedented ethical issues as is evident if we look retrospectively at the situations in Italy and New York State.

In an attempt to wade through the anticipated storm that would hit Malaysian shores while keeping my head held high, I contacted Sharon and HS on 13 March 2020 to discuss if they would be willing to form a WhatsApp group to discuss ethical issues surrounding the COVID-19 situation in Malaysia. One idea led to another, and as they say, the rest was history.

Thanks to their diligent and quick work, we managed to produce a draft piece on ethics for our local situation by the following week. This is the origins of the statement 'Towards an Ethical Response to COVID-19 in Malaysia'. We decided that needed a name to associate the statement with and for correspondence purposes, hence the birth of *Ethics Malaysia*.

We then listed out potential signatories from among those associated with bioethics and Malaysia whom we had the privilege of previous encounters. It took another couple of days to reach out to everyone and to gain consensus before we released the document on 22 March 2020 (we had initially targeted the release for 20 March 2020 at 20:20H).

As a follow-up to the statement, the birth of Ethics Malaysia was very quickly followed by the inaugural meeting of what is now known as the *Malaysian Bioethics Community (MBC)* the following Saturday afternoon (28 March 2020). The initial intention was to use this meeting as a meet-and-greet session for the signatories of the recently released statement. The now 'members' of the MBC then decided to re-convene on the following Saturday, and the Saturday after, and this has since become quite a successful community event.

Full of enthusiasm, this amazing community has walked on through the wind and rain of the COVID-19 storm and has grown tremendously in stride. These ethical reflections (a suggestion brainstormed during the second meeting) is the fruit of the labours of many of the MBC members after a couple of weeks of hard work. Some other projects that have been born through a similar fashion include the initiation of the Clinical Ethics Malaysia COVID-19 Clinical Ethics Consultation Service, and the COVID-19 Clinical Ethics Resource Library. More ideas continue to be generated, and the next step will involve a series of forums to engage the medical community and public with the contents published here.

As the storm clears, the government is starting to mull on exit strategies for the Movement Control Order. It has been a wonderful journey weathering the storm together, and I hope that the members of MBC will remain on the journey, charting new territories, as we steer through calmer waters towards the golden sky of Bioethics in Malaysia (and yes towards that conference that we initially planned for).

In retrospect, the COVID-19 pandemic has been a blessing in disguise for bioethics in Malaysia as it has provided the reason for the members of the MCB to unite. The bioethics landscape in Malaysia has been changed because we will no longer be walking individually, and I am sure greater achievements will be accomplished through collaboration between members of the MCB for together everyone achieves more.

"… walk on, walk on, with hope in your heart, and you'll never walk alone."

p.s. I do not happen to be a fan of the Liverpool Football Club.

This chapter can be cited as:
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APPENDIX 1

ICU Management Protocols 2019 - Malaysian Society of Intensive Care.

Source: http://msic.org.my/download/ICU_Protocol_Management.pdf

ICU admission based on priority In evaluating the appropriateness of ICU admission, the priority should be based on the needs of the patient and the likelihood of benefitting from admission. This prioritisation defines those who will benefit most from ICU (Priority 1) to those who will not benefit at all (Priority 3).

1. **Priority 1**
   a) Critically ill, unstable
   b) Require life support for organ failure, intensive monitoring and therapies that cannot be provided elsewhere. This includes invasive ventilation, renal replacement therapy, invasive haemodynamic monitoring and other interventions
   c) Do not have limitations of treatment
   d) High likelihood of benefit

2. **Priority 2**

   Priority 2A

   a) Acutely ill, relatively stable
   b) Requires intensive monitoring and/or therapies for organ dysfunction, that can be managed in an intermediate care facility (high dependency unit or post anaesthetic care unit)
   c) Admit to ICU, if early management fails to prevent deterioration or there is no intermediate care facility in the hospital
   d) Examples include:
      i. post-operative patients who require close monitoring
      ii. respiratory insufficiency on intermittent non-invasive ventilation

   Priority 2B

   a) Critically ill, unstable
   b) Require life support for organ failure
   c) With significantly lower probability of recovery because of advanced underlying disease
   d) May have specific limitations of care e.g. no cardiopulmonary resuscitation
   e) Lower likelihood of potential benefit
   f) Examples include:
      i. metastatic cancer in septic shock secondary to hospital acquired pneumonia but with some limitations of therapy e.g. no CPR
      ii. decompensated heart failure with deteriorating functional status and multiple hospital admissions

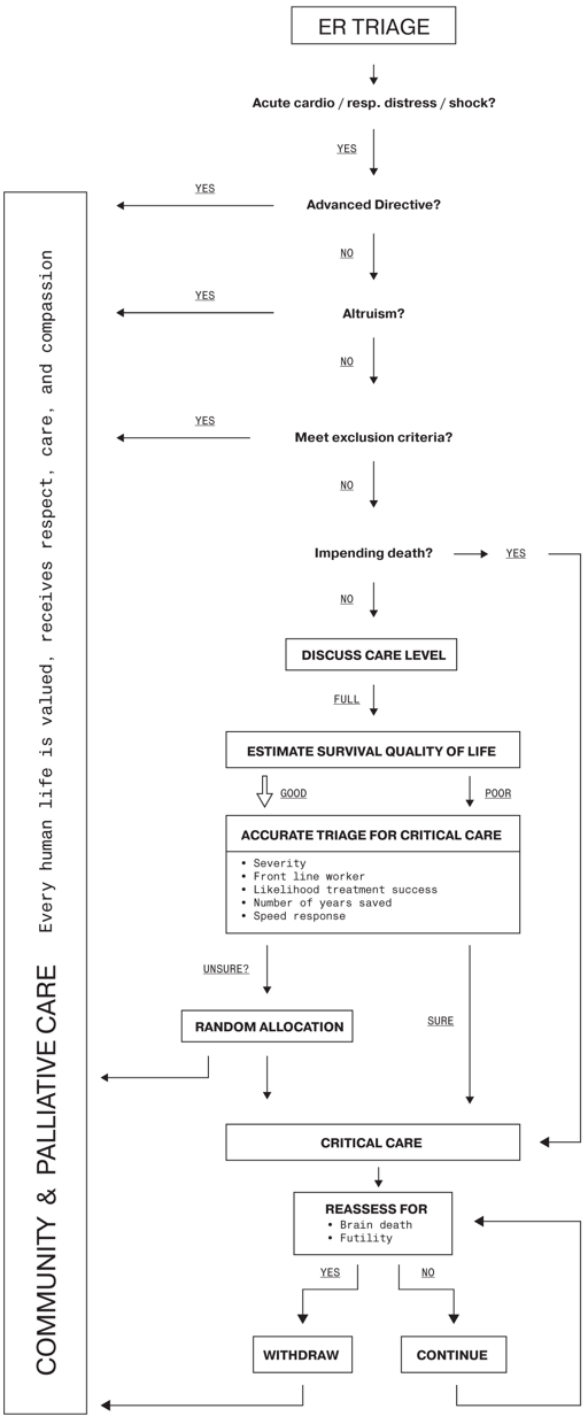
3. **Priority 3**
   a) Terminally ill or moribund patients with no possibility of recovery
   b) Not appropriate for ICU admission
   c) May benefit from palliative care rather than intensive care
   d) Examples include:
      i. severe irreversible brain pathology impairing cognition and consciousness or in a persistent vegetative state
      ii. metastatic cancer unresponsive to chemotherapy and/or radiotherapy
      iii. end-stage cardiac, respiratory or liver disease with no options for transplant
      iv. severe disability with poor quality of life
      v. advanced disease of a progressive life-limiting condition e.g. - motor neuron disease with rapid decline in physical status, - severe Parkinson's disease with reduced independence and needs assistance for activities of daily living
      vi. poor response to current treatment e.g.- bowel leak despite multiple laparotomies, - recurrent soft tissue or musculoskeletal infections despite multiple surgical, intervention,
      - chronic medical conditions that fail to respond to treatment such as SLE or HIV
      vii. end-stage renal disease with no option or refusal for renal replacement therapy
      viii. those who have explicitly stated their wish not to receive life-support therapy

APPENDIX 2

Proposed Triaging Protocol from The Research Center for Islamic Legislation and Ethics (CILE)

Source: https://www.cilecenter.org/resources/articles-essays/islamic-ethical-perspectives-allocation-limited-critical-care-resources)

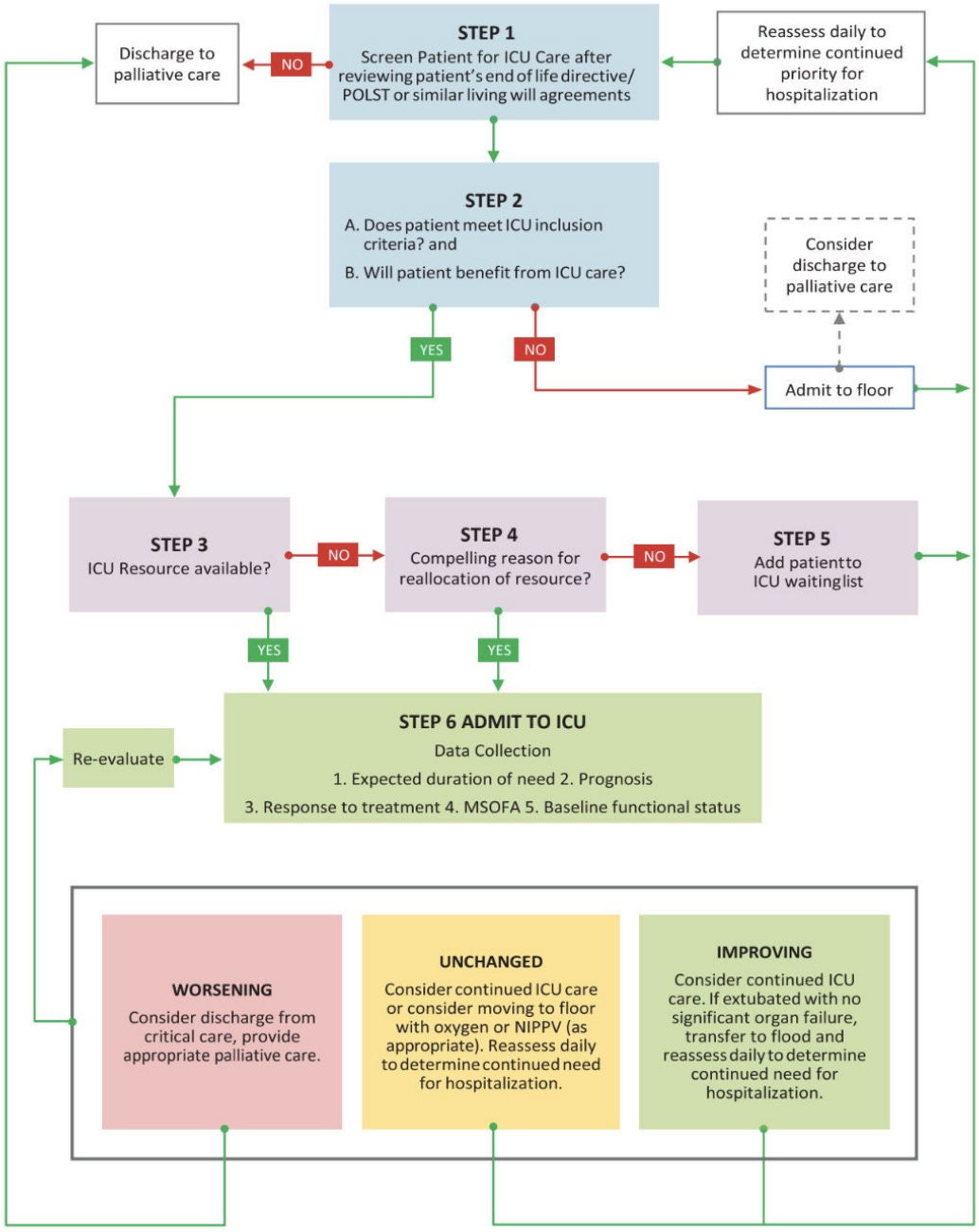
FIG 1 Ethical Management of Triage



APPENDIX 3

Triaging Protocol from Washington

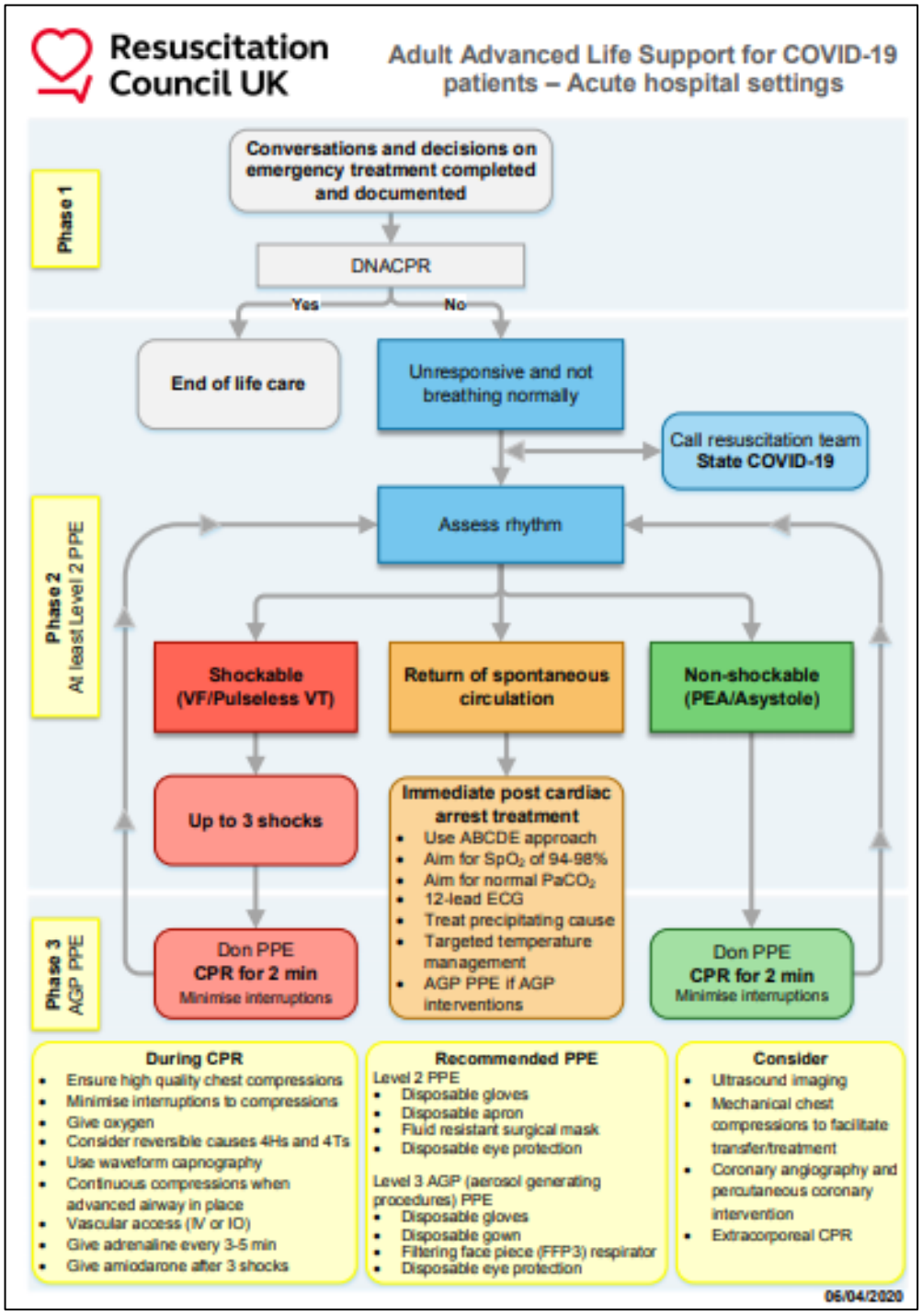
Source: Baker M, Fink S. At the Top of the Covid-19 Curve, How Do Hospitals Decide Who Gets Treatment?. Nytimes.com. https://www.nytimes.com/2020/03/31/us/coronavirus-covid-triage-rationing-ventilators.html. Published 2020.



APPENDIX 4

Resuscitation Council UK (Adult ALS for COVID-19)

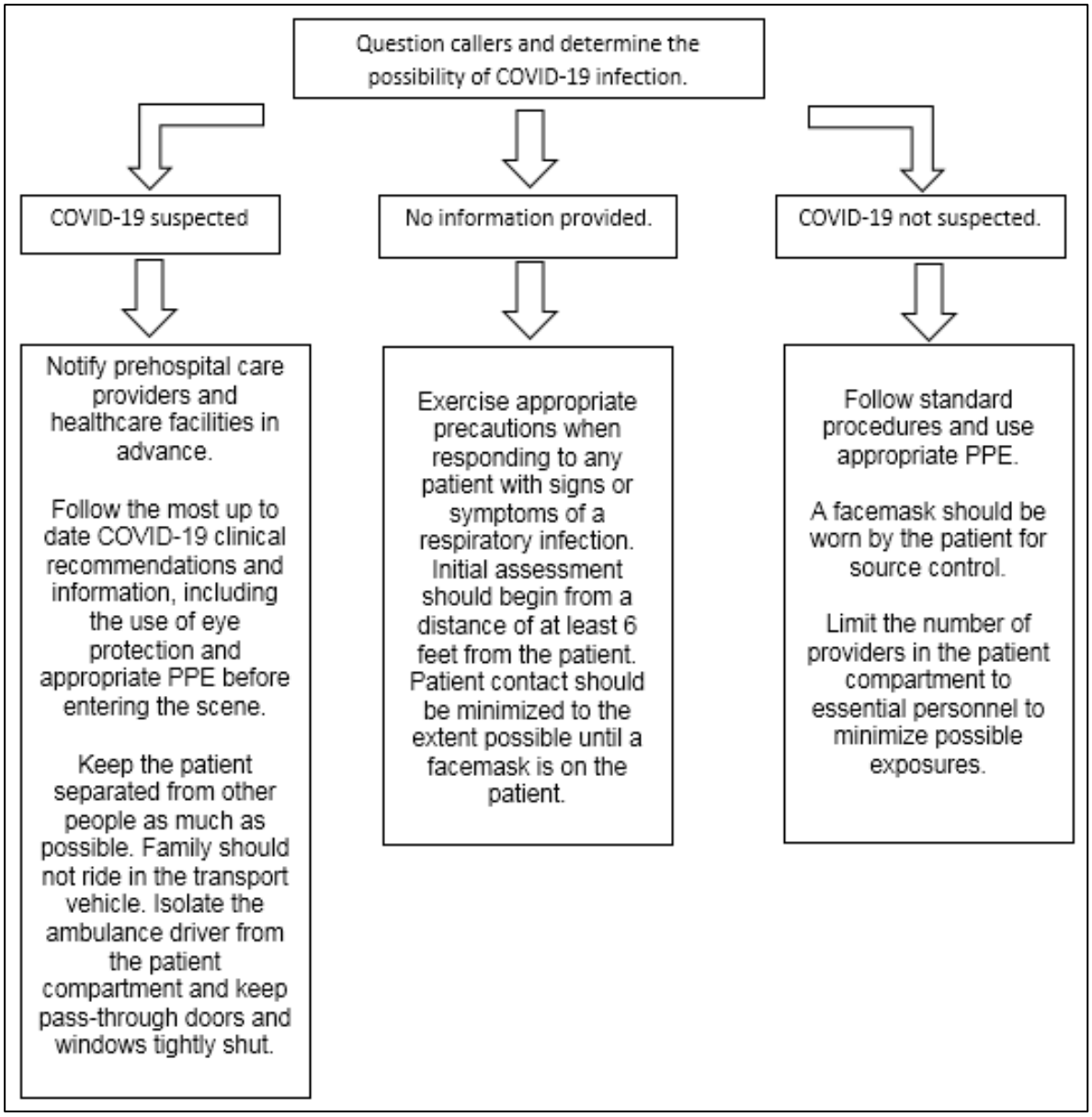
Source: https://www.resus.org.uk/media/statements/resuscitation-council-uk-statements-on-covid-19-coronavirus-cpr-and-resuscitation/covid-healthcare/



APPENDIX 5

Algorithm adapted from Interim Guidance for Healthcare Providers during COVID-19 Outbreak

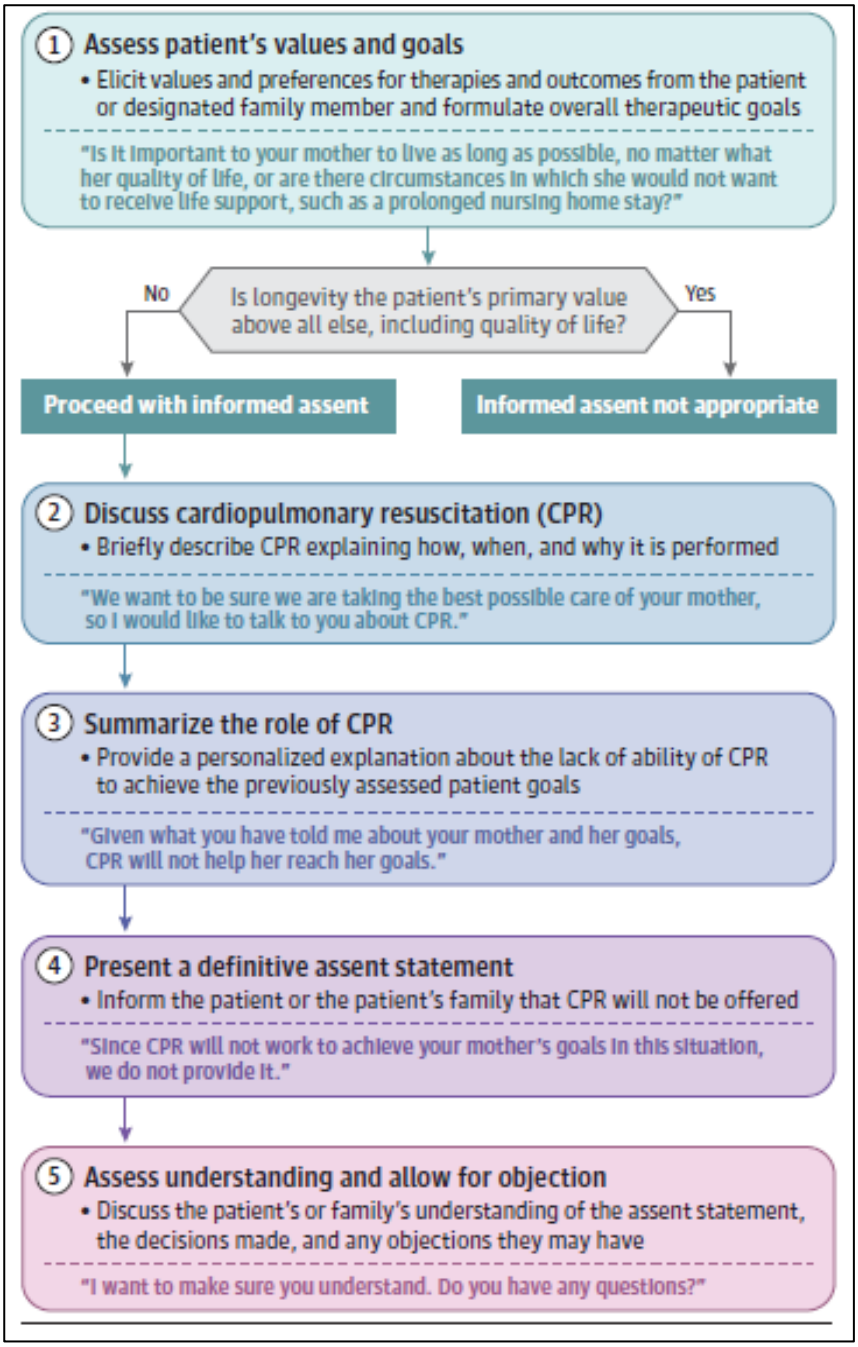
Source: https://professional.heart.org/idc/groups/ahamah-public/@wcm/@sop/@smd/documents/downloadable/ucm_505872.pdf



APPENDIX 6

American Medical Association (AMA): Proposed Components Of Informed Assent Framework

Source: Curtis J, Kross E, Stapleton R. The Importance of Addressing Advance Care Planning and Decisions About Do-Not-Resuscitate Orders During Novel Coronavirus 2019 (COVID-19). JAMA. 2020. doi:10.1001/jama.2020.4894



APPENDIX 7

Various COVID/CPR Scenarios

Liew Houng Bang

Scenario	Recommendation/Suggestion
In Hospital Cardiac Arrest (IHCA)	
Scenario 1: Resuscitation for Confirmed COVID-19 patient	• HCW should/would be already on strictest level of PPE. • Severity of patient and prognosis should be assessed. For patients with pre-existing co-morbidities, please also read points in scenario 4. • Probability of arrest and need for resuscitation should be discussed and anticipated. • Put defibrillator pads in anterior-posterior position. In children, place pads in the usual position below right clavicle and over the apex. • For patients who are in prone position, with advanced airway and ventilated, provide CPR with patient remaining in prone position. In children, may turn them over and provide in the usual manner. • To adjust respiratory rate to 10/min or 30/min in neonates. • Extra measures to prevent accidental extubation, by securing the endotracheal tube. • If a patient's airway is not secured yet at time of arrest, positive pressure ventilation (PPV) may be performed only if the attending HCWs are in full PPE with viral filter inserted.
Scenario 2: Resuscitation for Unconfirmed but Suspected COVID-19 Patient	• This include PUI/SARI. To be managed as COVID-19 until proven otherwise. • Therefore, the same principle applies in approach as in Scenario 1.
Scenario 3: Resuscitation for Unanticipated Arrest in a non-COVID-19 patient	• Patient who is admitted to the hospital for other diagnosis (non COVID-19). • Standard care should be provided if there is low suspicion or low probability of COVID-19. • There is no reason to withhold resuscitation in a setting of cardiorespiratory arrest. • Remind to escalate the level of PPE if AGP (e.g. emergency tracheal intubation); this include N95 mask and goggles/face shield. • Beware of the inherent delay of donning PPE. Balancing the protection of HCW involved vs delayed resuscitation measures which compromise patient's prognosis.
Scenario 4: Resuscitation for Anticipated Arrest in a non-COVID-19 patient	• Patients with no clinical evidence of COVID-19, which include: - Acute medical/surgical emergency with imminent risk of arrest (e.g. massive stroke, life threatening MI, acute abdomen, head trauma). Preexisting disease with progressive deterioration and limited life expectancy (e.g. advanced cancer, advanced heart failure, ESRF, dementia).

	Points to Consider 1. Prognosis. Consider both the acute and underlying chronic disease. 2. Previous discussion/decision regarding advance care planning or palliative care plan. 3. Assess for patient's mental capacity: - If impaired capacity: to engage patient's next-of-kin. - If has capacity: explore patient's understanding, expectation, health goal and life goal (shared decision) 4. Be wary of the clinical need and natural history of underlying disease vs the probability of a silent asymptomatic COVID-19 infection. The balance between precaution vs paranoia. - With regards to the above, the probability of a silent or asymptomatic infection need to be evaluated based on the local situation. Consultation with an Infectious Disease specialist and public health officer is prudent. - For instance, in a setting where COVID-19 is at early containment with no cluster or sustained community level transmission, vs in a setting where COVID-19 is widespread, and high proportion of patients with no epid-link. 5. Resource setting: beds, blood bank, ICU, ventilator, isolation facilities, PPE stock.
Out of Hospital Cardiac Arrest (OHCA)	
Scenario 5: **In response to prehospital dispatch**	• Institutional guidelines should have a checklist of patient's history, symptoms and signs, to access risk of COVID-19. • Don appropriate level of PPE, in anticipation of infection risk, prior to dispatch. **Points to Consider** 1. Probability of asymptomatic COVID-19 infection. 2. Public layperson CPR may pose risk of cross infection. The decision to initiate hands-only CPR is beyond the scope of our recommendation. 3. Public AED should be used if available (presume probable ventricular arrhythmia).
Scenario 6: Cardiac arrest upon arrival at healthcare facility (including, pulseless, gasping or unresponsive)	• **Don strict level PPE before commencing resuscitation.** • Recommend a few measures: 1. Majority of OHCA may be due to common causes, e.g. VT/VF in myocardial infarction. 2. Upon arrival, acquire ECG using 3-lead as soon as possible, for early detection & diagnosis of patient's rhythm. 3. If shockable arrhythmia, early defibrillation confers better survival (use adhesive pads to allow distance). 4. If ECG shows nonshockable rhythm, e.g. bradycardia, initiate transcutaneous pacing (use adhesive pads to allow distance). 5. HCW who has donned Category II+ PPE (incl N95 mask, goggle/shield) may initiate hands-only CPR. 6. HCW MUST don Category III PPE for AGP.

APPENDIX 8

More Scripts For RED-MAP

Chong Lee Ai

Ready:
Family
"Thank you for calling me back…" "Would you have some time to talk…"
"I'm calling you to ….let you know how things are going with your…discuss about your …update you on…"

Patient
Warning shot:
"You have been in hospital for X days, we would like to talk about how things have been going?
" You might be wondering why you still don't feel so well/so good"
" Will it be alright/ok to talk to you about how this virus is affecting you?"
" You had an XR this morning…"

Expect
Family
"What do you understand so far about how your … is?"
"Has anyone spoken to you about your …condition?"
Acknowledge their concerns or emotions when expressed

Patient
"Can you tell you what you understand so far about your health?"
"Can you tell me what you know about this infection you have?"
"Would you be able to tell me how you think your treatment is going?
"Can you tell me know how you feel today?"

Diagnosis
"Ask Tell Ask"
Acknowledge emotions
Empathy - verbal , non-verbal
Pause/ active listening

Matters
"Knowing what you know now, what do you think is most important to you?"
"We hope all that we are doing now will make you feel better……(pause) "
"We worry things may not go the way we want it to…"
"We would like to make plans with you for your care, is there anything that you would like us to know?"
"…would you be ok if we think about your care if things don't go the way we hope?"
"We have just started…. we hope it will make you feel better. I wonder if we could also think about the chance that it doesn't work…"

“These are quite big decisions….who would you like to be here with you?”
“Who do you think knows you best and can speak on your behalf about your medical things”
“Would you like us to speak to someone else about the medical decisions you have to make?”

Actions
“At the moment what we are doing is…”
“From what you have told me, it looks like you might prefer….”
“Please let me know if I understood you correctly…..”
“Because you value….we will do….”
“It sounds like it’s important for you ….., so we will….”

APPENDIX 9

WHO Psychological First Aid: Guide For Field Workers, 2011

Source: https://www.who.int/mental_health/publications/guide_field_workers/en/

Prepare

- Obtain information from reliable sources (e.g. WHO/CDC/MOH/Hospital administration). Understand the crisis situation and changes made at your workplace.
- Get to know the access to certain services at your workplace, such as mental health support or psychology and counselling service.

Look

- Identify colleagues who appear upset/distressed and who are likely to need special attention and psychological support. For example, colleagues who have been redeployed, quarantined, or who family have been quarantined/diagnosed with the disease.
- Be reminded on distress responses among colleagues:
  - Irritability, anger
  - Guilt, shame (e.g. for not able to help at work when required home quarantine)
  - Crying, sadness, depressed mood, grief (e.g. fear of carrying the disease and infecting family)
  - Appearing withdrawn or not responding to others.

Listen

- Find out what is most important to them at this moment. Help them work out what their priorities are.
- Listen when they want to talk, but do not pressure the person to talk.
- Help them to feel calm and try to make sure they are not alone.
- Keep your tone of voice calm and soft.

Link

Link them to practical support (e.g. mental health support service, HOD/Hospital Director)

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bukan sia-sia segala nafasku hembus,
bukan sia-sia segala
lelahku berjuang,
bukan sia-sia segala hatiku galau.
bukan sia-sia segala airmataku titis,
bukan sia-sia segala senyumku lempar,
bukan sia-sia segala impianku lakar,
bukan sia-sia; segala
penantian dan kasihku curah.
bukan sia-sia.

Syasya Muda