

Palliative care during the COVID-19 pandemic

Understanding the
necessity for honest
conversations and difficult
decisions

Written for the Australian COVID-19 Palliative Care Working Group by:

Dr Will Cairns OAM - BA MBBS FRACGP FChPM
Palliative Medicine Consultant, Townsville, Queensland

Rachel Coghlan - B.Phys (Hons), MPH
Researcher, Centre for Humanitarian Leadership, Deakin University

Published by Palliative Care Australia



PalliativeCare
AUSTRALIA

Abstract

Over the course of the COVID-19 pandemic, Australian palliative care clinicians are facing the likelihood of significant challenges to the delivery, availability and quality of palliative care for existing palliative care patients, new palliative care patients with diseases other than COVID-19, and those who might die from COVID-19. One of the greatest concerns throughout this pandemic has been that a surge in demand for healthcare resources from patients with COVID-19 will overwhelm existing capacity and disrupt the care of people with other conditions, as has been seen in countries with high rates of COVID-19 infection. Given the uncertainties of COVID-19, it is vital that we prepare for the full range of possibilities for healthcare and health resources, including the worst-case scenarios of morally distressing decision-making in pandemic triage. Australia has not yet comprehensively addressed these issues nor produced the tools – guidelines, protocols and ethical justifications – necessary to support clinicians who would have to implement the unavoidable and heart-wrenching choices of resource allocation and triage.

This paper has been written to guide an understanding of the scope of challenges that a pandemic or disaster poses for the delivery of health services, in particular for palliative care. It describes the role of palliative care in supporting different patient journeys during COVID-19, including the importance of Advance Care Planning, the ethical challenges and distress that may arise in the event that resource allocation or rationing decisions become necessary, the overarching principles that govern the distribution of finite resources, and the practical realities of how such principles are implemented. It invites governments – Commonwealth, State and Territory – to take the lead in working with clinicians and communities through open and transparent processes to create the necessary guidelines for difficult decision-making during a disaster or pandemic. Finally, the paper discusses the role of governments in accepting legal and moral responsibility for guidelines that instruct the difficult binary choices of treatment refusal when resources cannot meet the demand for life-prolonging treatment during a major disaster or severe epidemic or pandemic such as COVID-19.



ANZ JPM



Written for the Australian COVID-19 Palliative Care Working Group by:

Dr Will Cairns OAM – BA MBBS FRACGP FACHPM
Palliative Medicine Consultant, Townsville, Queensland

Rachel Coghlan – B.Phys (Hons), MPH
Researcher, Centre for Humanitarian Leadership, Deakin University

Published by Palliative Care Australia

Preamble

Two days ago, ... we learned some workers had tested positive at the residency where my mother is!! I couldn't sleep the first night, especially thinking that one couldn't travel and hold hands, etc etc... it made me have a remote glimpse about the things one reads of relatives not being able to say good bye, etc etc... all very sad. Thankfully my mother's test came back negative.... it is still very worrying but at least at this moment is good! I want to ask what happens when it is decided that a very old person will not get the ventilator so a younger one can have it... (a necessary decision in some cases). Can the doctors make the journey easy in this case? Hard to imagine if breathing is not easy! Well, you can see what has been in my mind!

**- Anonymous personal email from a friend of one of the authors
April 2020**

This one paragraph covers much of the range of human responses to the impact of COVID-19: fear of death and of loss, separation, enforced isolation and the inability to provide support, recognition that difficult decisions may be required that deny some patients access to treatment, fear of suffering, and concern that appropriate palliative care will not be available. In a subsequent conversation, this person volunteered the observation that many people are experiencing similar emotions.

Much will remain unknown about this virus until its longer-term effects on both individuals and the community start to reveal themselves. Will individuals who are infected by the virus become immune, and if so, for how long might they remain immune? Will the virus eventually evolve to become less virulent? Will we become afflicted by another continually evolving and recurring perennial infection, like the coronaviruses that cause the common cold? Could it just fade away altogether like SARS, yet another coronavirus? Will we develop an effective vaccine, how long might that take and for how long will it remain effective? How will human cultures, values, beliefs and behaviours be changed by this pandemic and how will the functioning of our communities change in response? The consequences of this pandemic will reverberate into our future, just as our current state is in part the product of our experiences of the countless pandemics and epidemics of our past.

While we wait for the answers to these questions, it is vitally important that both clinicians and communities understand that the pandemic will persist for months, and perhaps even years.

Furthermore, it will disrupt many aspects of our lives long after the direct impacts of the virus itself have diminished. What we can do is decide what actions are necessary to prepare and implement for what we believe might happen in the future. This is true for palliative care as much as it is for all other components of our society and of our healthcare system.

Our last significant pandemic was over 100 years ago – the influenza pandemic of 1918-1919.^{1,2,3} Many tens of millions of people died, predominantly children and young adults who had not acquired immunity during an earlier epidemic prior to about 1850. In 1918-1919, there were no antibiotics, no antivirals, no Intensive Care Units (ICUs) and no ventilators. The community had no expectation that they would receive treatment with any significant chance of stopping them from dying.

We live in a very different world now. Modern societies have developed a consumerist approach to healthcare – we believe that we have the right to receive best-practice treatment. Many more of us, particularly the elderly, live lives supported by technology. In countries like Australia, we have a learned expectation that our lives can be sustained in ICU and by ventilators. Our healthcare systems are of a size that can cope with a small short-term increase in demand, but not with a huge and prolonged increase. For many, the greatest concern in the COVID-19 pandemic is that a surge in demand will overwhelm the capacity of acute medical services, disrupt the care of people with other conditions, and infect numerous healthcare workers, further decreasing supply. All of these have been seen in countries with high rates of COVID-19 infections.

.....
1. Spinney L. *Pale Rider: the Spanish flu of 1918 and how it changed the world*, Random House, 2017
2. Bristow N.K. "It's as Bad as Anything Can Be": Patients, Identity, and the Influenza Pandemic *Public Health Rep.* 2010; Vol.125(Suppl 3), pp.134-144, doi: 10.1177/003335491012505316
3. Taubenberger J. and Morens D. 1918 Influenza: the Mother of All Pandemics, *Emerging Infectious Diseases*, Vol. 12, No. 1, January 2006, www.cdc.gov/eid

Even without a large-scale disruption to the delivery of healthcare by overwhelming numbers of patients with COVID-19, the disruption consequent from our efforts to contain its spread means we are likely to face ongoing limitations to the quantity and quality of healthcare that can be delivered. This will impact across the health system including palliative care services. And given the uncertainties, it is vital that we prepare for the full range of possibilities, including the worst-case scenarios that may eventuate during this pandemic or any future disease outbreaks.

The growing demand for palliative care from our ageing population was already posing significant challenges to the provision – delivery, availability and quality – of palliative care to existing patients before COVID-19. Changes to the delivery of

palliative care services necessitated by measures to control COVID-19 have caused further strain on the overall provision of palliative care in Australia, for both the admission of new palliative care patients with diseases other than COVID-19, and for those few who have so far died from COVID-19. While it will be some time before we fully understand the impact of COVID-19 on the delivery of palliative care, for both clinicians and their patients, the things that we learn will help planning for future events.

This paper is being written to help us all understand the scope of challenges that COVID-19 poses for the delivery of palliative care services in our community. It has been structured to help us organise a diversity of ideas and to inform, and, as such, is not concise but inclusive.

Introduction and overview of the paper

This paper has been prepared as part of the promotion of openness, candour and honesty that respects our community's ability to engage with confronting issues and deal with realities that cannot be dodged. In difficult times, a well-informed community is much better equipped to make the changes necessitated by circumstance. And when dealing with unpreventable deaths during the time of the pandemic, some of which might follow on from triage decisions made in the interests of the community at large, we all need to know that every individual who is dying will continue to be cared for.

Most of the activities described herein will be familiar to clinicians who engage in [Whole Person Care](#)⁴

Even though the scale and urgency of activity may be accelerated by the pandemic and some practices will be constrained by resource limitations and the demands of infection control, much of what we will do over the course of this pandemic is at the core of good clinical practice and will remain unchanged. At all times, high quality healthcare is founded on engaging with the patient, understanding their values, their goals and their illness, and helping them to make choices from the options that are available to them.

Even in times of plenty and in affluent nations, there are never enough resources to meet all perceived healthcare needs. Most developed nations have relatively uncontroversial mechanisms in place for ensuring that finite resources are distributed in a relatively equitable manner.⁵ Over the course of an emerging pandemic, these processes become much more urgent and overt when the resources necessary to provide treatment are in short supply and the measures that are imposed to contain transmission of the pathogen interfere with healthcare systems. Concurrently, it becomes increasingly important that we understand the overarching core values and principles that govern the distribution of finite resources, and the practical realities of how they are implemented. These changes require honest, open discussion and leadership from governments in order that the community accepts that action is being taken in their interests.

This paper starts with a description of the core business of palliative care during a pandemic (*The role of palliative care during the COVID-19 pandemic*). This is followed by a mapping exercise that describes the sequential processes of decision-making with patients (*Understanding patients' journeys with COVID-19 and the role of palliative care*). This is important because the vast majority of patients with COVID-19 do not require anything more than supportive measures as they recover from physical consequences of the illness. For them, most of the disruption to their lives stems from the need to reduce the risk to others.

We feel that this first step of describing the range of clinical scenarios with COVID-19, and their frequencies, is important so that we can all understand that decision-making and resource allocation are not as difficult for the vast majority of people, including many of the seriously ill, as we might fear. Many of the decisions that we worry about can be defused by the long-established practice of good communication. It is important to make time to explain to patients and their families the nature of the disease and its possible interaction with any comorbidities that they may have, its likely course and the benefit and burdens of treatment, and exploring with them their hopes, wishes, goals and preferences, and whether these might be achievable. These conversations can be used to design mutually agreed plans for future care and treatment should it become necessary.

The vast bulk of such open decision-making activity is included under the umbrella of Advance Care Planning (ACP). ACP is uncontroversial and conventional practice in non-pandemic times. Although perhaps more urgent during a pandemic, ACP should be no more controversial or difficult than when an individual is faced with any other serious illness. At the same time, it is very important to guard against ACP being corrupted to disguise a decision based on lack of resources not to provide treatment to a patient, as a decision by the patient to not accept that treatment. In our section on *Advance Care Planning*, we have included a brief description of ACP including mention of the different rules and legislation across Australian States and Territories, and links to [ACP Australia](#).

4. Hutchinson T. ed. *Whole Person Care: A New Paradigm for the 21st Century*, Springer, New York 2011

5. See, for example, National Institute for Health and Care Excellence (NICE) Guidelines and processes in the UK - <https://www.nice.org.uk/about>

Only after these issues have been discussed do we address the ethical challenges that can arise for the minority of cases of COVID-19, should it become necessary to engage in resource allocation decisions because the supply of healthcare resources does not match the demand to contemporary standards (*Resource allocation, rationing and triage*). As will become clear in subsequent sections of this paper, this unfolds in a variety of ways, including in those times when decisions must be made about which people will and will not be treated because there are not enough resources to treat everyone (*Pandemic triage decision-making and the principles of ethics*).

We then turn to the practical aspects of making difficult decisions (*Turning ethical principles into practice*), who bears responsibility for taking leadership in difficult decision-making in a disaster or pandemic (*Taking responsibility*), how to manage the consequences of such decisions (*Dealing with the hazards, burdens and distress of pandemic triage*), and finally, our observations of current Guideline development for making difficult decisions in Australia (*Open and transparent availability of documents that support wise resource allocation and triage decisions in Australia*).

The role of palliative care in the COVID-19 pandemic

As has been experienced by humans for a few thousand years, epidemic infections disrupt the complex and interdependent functioning of communities and kill large numbers of people. The current pandemic is no exception. It is now abundantly clear that COVID-19 will kill a not-insignificant proportion of populations in which it is allowed to spread unchecked, although nothing near the numbers who have died in many of the epidemics of our historical past.

The normal operation of societies (and their economies) around the world is being upended with severe damage to the personal and financial security of countless people and their families. COVID-19 is destabilising health systems that are struggling to deal with a flood of seriously ill patients on top of their pre-existing workload. The pandemic is exposing the structural and functional weaknesses of many societies and may cause some healthcare systems to collapse, and nations to fail altogether.

Because of the relatively short time from exposure to infection to further transmission, the numbers of very sick people can ramp up quickly with the risk that hospitals can rapidly become overwhelmed.

As the demand for critical care resources during a pandemic will likely be sudden and occur over a short time frame it will be too late at that point for a hospital and ICU to create a plan to respond to the surge in volume of critically ill patients.⁶

Over the course of the COVID-19 pandemic, we have heard the distressing tales from Italy, the UK, Iran, Russia and New York of people dying alone, with their family excluded, stranded in the alien world of ICU while surrounded by gowned, masked and goggled figures.⁷ To many unwell and delirious patients, it must be a nightmare, like a scene from *Chernobyl*.⁸

While most of us are troubled by these descriptions, the workers who must enact these measures within healthcare systems are among the most affected – the emergency responders in the community, hospital emergency and acute care staff, and workers in ICU who must become virtually anonymous to protect themselves, their colleagues and the community at large from

COVID-19. At the same time, we must recognise that many clinicians have been remarkably effective in their communication and have been able to project their humanity in spite of these constraints.

Palliative care services and their existing clients are also being caught up in the disruption. With so much attention focused on ventilators, ICU and efforts to decrease the transmission of COVID-19, it is easy to forget that, like many other aspects of healthcare delivery (for example, dialysis), the provision of palliative care to patients dying from diseases other than COVID-19 must go on. Additionally, the availability of comprehensive palliative care, always a key component of healthcare, is never more important than at a time of increased mortality, and increased anxiety and vulnerability, as in a pandemic.

Such necessities of the response to the threat of COVID-19 are almost the antithesis of our work in palliative care. Our task is to journey alongside our patients as they live through their last days, weeks or months of life until their death: managing their symptoms, supporting their family, helping them to be, if possible, in a place of their choosing, addressing their fears, anxieties and worries, and engaging with them on a personal level.⁹ High-quality palliative care is founded on spending time in close physical and emotional contact with those who are dying and their families.

By necessity, these core activities are being obstructed and marginalised in the scramble to treat as many people as possible so that they can be prevented from dying from COVID-19, and to further curb the spread of the virus. The harm that this is causing to us as obligate social beings who are asked to remain socially distant is becoming increasingly evident. It is vitally important that as soon as it is safe, we restore the humanitarian heart of palliative care in a world where the dehumanising aspects of medical technology have assumed priority.

6. Manuell ME., Co M. and Ellison R. Pandemic Influenza: Implications for Preparation and Delivery of Critical Care Services. *J Intensive Care Med*, 2011 Nov-Dec; Vol.26(6), pp.347-367. doi: 10.1177/0885066610393314 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4110744/>

7. Coronavirus: Stories from the frontline. ABC Q+A, 6 April 2020. <https://www.abc.net.au/qanda/2020-06-04/12111220>

8. *Chernobyl* miniseries, HBO. <https://www.hbo.com/chernobyl>

9. *Therapeutic Guidelines: Palliative Care* (version 4), Therapeutic Guidelines Ltd 2016

Palliative care services face a number of specific challenges during a pandemic. Unlike many of the elective activities of healthcare, key life events such as childbirth and dying cannot be postponed or cancelled because there are other more pressing matters. Nor can the grief that surrounds a death. High-quality palliative care must continue to be provided to those who had been referred prior to the outbreak of the pandemic; for example, for people with life-limiting illnesses such as cancer, cardiac failure and motor neurone disease. Additionally, patients will continue to be diagnosed with new or progressing fatal illnesses other than COVID-19 during the course of the pandemic and will require palliative care. Most importantly, palliative care services and practitioners have a new role in caring for those who are dying from COVID-19.

This last challenge will be made more difficult if some patients are referred for palliative care because, due to limits to supply, they cannot be offered the intensive life-prolonging treatments that we have learned to take for granted in the developed world, even though they may have benefited. Faced with the potential for our healthcare systems to be overwhelmed by large numbers of seriously and critically ill people, for the first time in the living memory of most in our community, we are preparing to choose which of the sickest people for whom treatment is indicated will be treated.

In the UK, referrals for palliative care have escalated, for both patients with and without COVID-19.¹⁰ Many governments have suddenly come to realise that palliative care is an essential component of the response to pandemics and disasters generally, and are incorporating the provision of palliative care into disaster planning algorithms and treatment plans and protocols. In New York, where health systems have been overwhelmed, in some hospitals palliative care services have become the de-facto go-to team for difficult decision-making discussions about withholding and withdrawing life sustaining measures.

It remains to be seen whether or not such worst-case scenarios will eventuate in Australia. However, it is generally accepted as prudent and necessary that policymakers and managers, clinicians and community members face up to our fears and prepare openly for the challenges of the decisions that must be made if these worst-case scenarios of inadequate supply of treatment resources

eventuate. Australia has not yet addressed these issues nor produced the tools – the guidelines, protocols and ethical justifications – necessary to support the clinicians who would have to implement the unavoidable and emotionally-challenging choices of resource allocation that will deny some medically eligible patients access to life-prolonging treatments. Whatever the course of the COVID-19 pandemic, such documents and the experience of their creation will become integrated into the essential preparation for our response to future epidemics or pandemics.

The experience of many on the front line is that patients and their families are able to understand and accept the necessity for difficult decisions.¹¹ During a pandemic, the obligation to provide palliative care as a basic human right may be overlooked temporarily in the urgent need to prevent deaths at a time when resources are scarce. However, the community's acceptance of stringent measures is based on the explicit understanding that they will not be abandoned simply because life-prolonging treatment is unavailable or denied, and that such measures will be accepted and adhered to by everyone. All patients should be able to receive palliative care to Australian standards, recognising that, in a severe pandemic, some rationing of resources may be necessary. It is also likely that palliative care providers will inevitably be tasked with explaining the triage criteria that led to the denial of treatment to some grieving patients and families.

In summary, during the COVID-19 pandemic, specialist palliative care providers will continue with traditional roles and take on a number of new roles. These include:

- » Providing palliative care education to health workers so that they can provide care to their dying patients affected directly or indirectly by COVID-19. This would become particularly important in the event of a significant surge in cases with an associated increase in mortality and demand for palliative care.
- » Supporting patients and their families who are facing death:
 - Existing and new patients with diseases other than COVID-19.
 - Patients seriously ill and dying from COVID-19.
- » Communicating with patients and families about grave issues of dealing with a life-limiting illness and the uncertainties of COVID-19.

10. Bajwah S. and Wiseman R., *Australian and New Zealand Society of Palliative Medicine (ANZSPM) Webinar - Palliative Care during the COVID-19 pandemic- experiences from a busy London Hospital*, 18 May 2020

11. Cairns W. and Coghlan R. COVID-19's ethical dilemmas: conversations at the dinner table, *MJA Insight+*, 4 May 2020, <https://insightplus.mja.com.au/2020/17/covid-19s-ethical-dilemmas-conversations-at-the-dinner-table>

- » Providing bereavement support for families dealing with the difficult challenges of grief in the circumstances of a death from COVID-19.
- » Promoting open and early ACP to ensure that the treatments people receive are in line with their wishes, goals and preferences.
- » Supporting colleagues in the community and rural/remote centres in the provision of ACP and palliative care.
- » Supporting the prompt recognition of when patients are dying so that the goals of care can change to the pursuit of the best possible palliative care for them and their families.
- » Providing personal support for non-palliative care clinicians who may be struggling to balance their desire to get the best outcomes for their

individual patients; the overwhelming patient load, their desire to deliver whole person care, the challenges of infection control, fears for their own safety and that of their family and colleagues, and all the while having to deal with the unfamiliar threat or reality of significant numbers of patients who are dying under their care.

Many of these roles are made far more complex by resource limitations during a pandemic. Palliative care services and practitioners should consider in advance how they can best prepare themselves to be most effective in supporting the care of patients who are dying during this pandemic. In order to do so, it helps to understand how people progress along the variety of journeys with COVID-19.

Understanding patients' journeys with COVID-19 and the role of palliative care

The scope of the experiences of individuals with COVID-19 is perhaps best understood as a diagram that describes the common routes taken on such journeys, with the proviso that there are always exceptions and individuals who follow paths less trodden, and that some patients may return to hospital care on more than one occasion. *Figure 1* describes the pathways by which people with COVID-19 may come to receive supportive and palliative care, whether by the realities of their overall health, their own choices, progression of their coronavirus infection, or the necessities of resource allocation if the demand for treatment overwhelms the supply of critical care. At its core, *Figure 1* is a simple patient flow chart with a series of basic categorisation decisions.

Patient journeys and clinical decision-making

The World Health Organisation has reported that most people infected with COVID-19 (more than 80% of infections) are asymptomatic or recover after a short illness with mild symptoms.¹² Clinical decision-making for these patients with less severe COVID-19 infection is generally uncontroversial.

The majority of those who become more seriously ill do not die, even though they, and their family, may go through a period of fearing that they will do so. It is amongst the less than 20% who experience more significant disease that the variety of difficult choices start to appear. Palliative care services generally do not become involved in the care of the large numbers of patients who recover from COVID-19 – most patients are referred for palliative care involvement because they are known to be dying or as a parallel stream of care if it seems possible that they might do so.¹³

Most of those who become seriously ill and are fit enough to be treated intensively do not choose to opt out of treatment. They are treated with escalating technology including ventilation and dialysis, and sometimes even Extracorporeal Membrane Oxygenation (ECMO), until it is clear that they are either recovering or that even the most invasive technologies have failed, and they are dying. At that point, the individual's life-

expectancy is usually very short, and they will almost certainly die in ICU when ventilation and/or other supportive measures are ceased. In the UK, palliative care clinicians caring for large numbers of patients in COVID-19 wards other than ICU reported that they were not often called to ICU to provide support.¹⁴ This is presumably because ICU teams are experienced in the provision of end-of-life care to people (and their families) who are dying, or have not recovered, in spite of maximal therapy.

However, amongst these sicker people, a proportion do not need to be subjected to any form of disaster triage or resource allocation decisions because their pre-existing co-morbidities or personal choices either set ceilings on their treatment or exclude them from intensive treatment for COVID-19. These are ethical and uncontroversial components of everyday practice. Good medical practice requires that clinicians should routinely weigh up the potential risks and benefits of the treatments that they are able to deliver and work out with their patients how these align with their hopes, goals and preferences.

It is also important to remember that many of these patients, even those with significant co-morbidities and a high mortality risk will, with basic supportive care (for example, oxygen therapy), recover from even a severe case of COVID-19, and so should not be presumed to be dying. While given every opportunity to recover and respecting any ceiling on their treatment, these patients would be managed conservatively, and subsequently with palliative intent if they are deteriorating inexorably or diagnosed as dying. In the UK, many hospitals have engaged in parallel supportive and palliative care to prepare patients at high risk of dying, their families and healthcare workers for either possible outcome.¹⁵

Finally, patients who have not responded to a period of intensive therapy may choose or agree, or their families agree on their behalf, to the withdrawal of life-prolonging treatment.

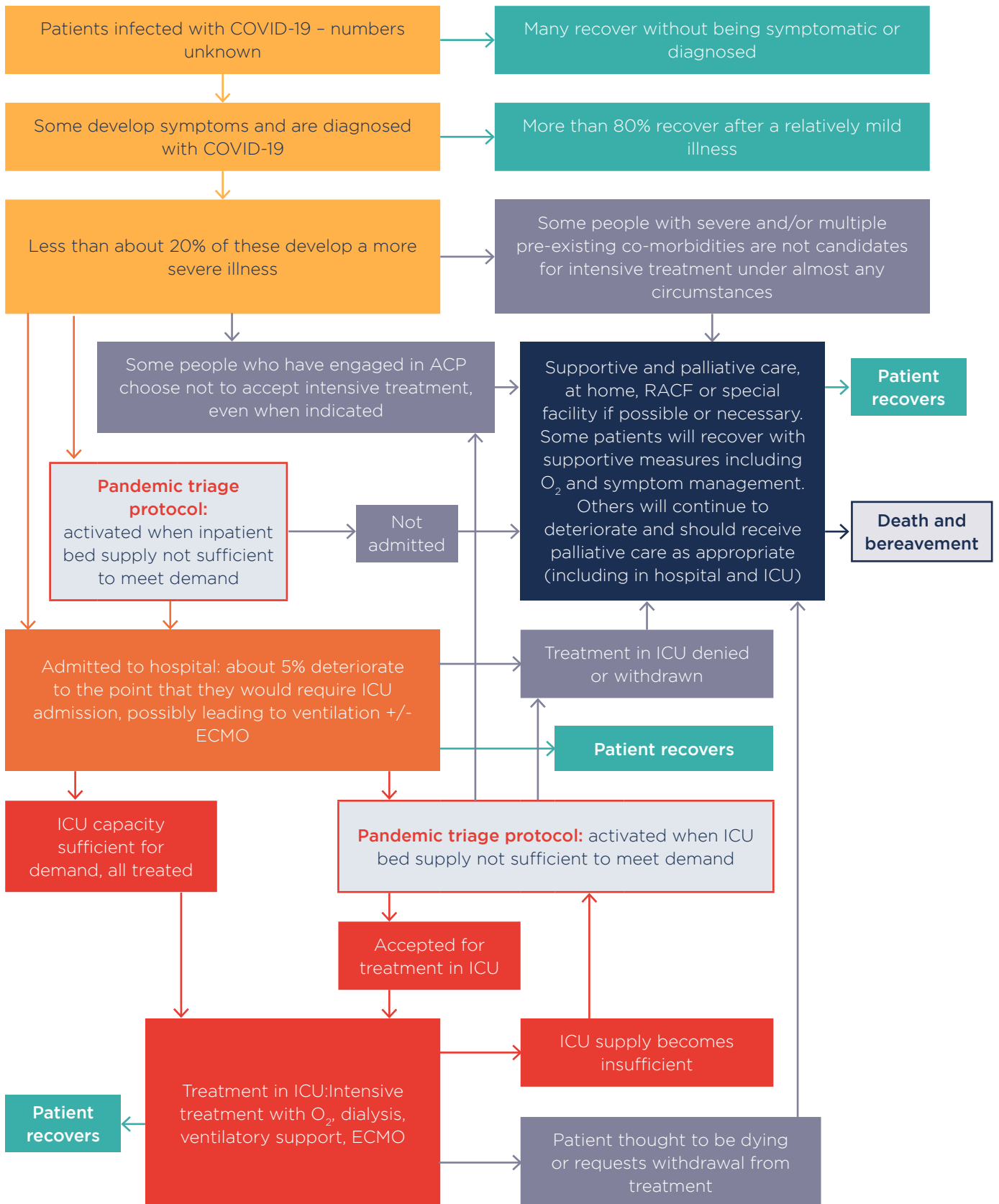
12. World Health Organisation. *Coronavirus disease 2019, Situation Report 46*. WHO, Geneva, 6 March 2020. https://www.who.int/docs/default-source/coronaviruse/situation-reports/20200306-sitrep-46-covid-19.pdf?sfvrsn=96b04adf_2

13. Bajwah S. and Wiseman R. 2020

14. *ibid*

15. *ibid*

Figure 1. The role of palliative care in the flow of patients with COVID-19



In summary, the patients who are either refused or excluded from intensive treatment at any time, including during a pandemic, include:

» **Patients who are not fit for intensive treatment**

All time spent in ICU places huge stresses on patients and there are a number of patients who would not survive intensive treatment or an admission to ICU or, if they survived, would be severely damaged by the experience. Many people with multiple and/or severe co-morbidities including severe dementia and frailty in old age can be identified on initial assessment as being too unwell for intensive treatment and/or admission to ICU under almost any circumstances. Such patients would have generally been denied ICU admission for intensive treatment even in the absence of a pandemic. These assessments are currently made routinely by ICU staff in consultation with the patient and/or their family.

Early assessment and ACP with patients who have significant and/or multiple illnesses, and discussions with their families, help to prepare for the likelihood that such decisions will be made. This can mean that such patients may be able to remain in their preferred place of residence until they die, an outcome that is in their interests as well as those of the community and its health services as a whole.

» **Patients who choose not to consent to intensive treatment**

A growing number of people are engaging in ACP and choosing to limit the scope of treatment that they will receive. Many are elderly and/or have significant illnesses that diminish the quality of their life. Others are simply elderly and perhaps somewhat frail and, being content with the life they have lived, do not fear death and prefer not to receive unpleasant life-prolonging treatment that may leave them permanently unwell and living a greatly diminished quality of life. Many set a ceiling on their care – for example, supplemental oxygen therapy but not assisted ventilation, or intubation and ventilation.

ACP conversations are a routine part of care and included as a core component of the document *Good Medical Practice: a code of conduct for doctors in Australia*.¹⁶ Although best done in advance, if it has not been done already, ACP should generally be undertaken at the time of admission in discussion between clinicians and their patient, or the patient's substitute decision-maker.

As a consequence, but not a goal, early ACP can reduce the demand for intensive treatment by supporting the self-exclusion of those who do not want it.

» **Patients for whom treatment has not been successful**

Patients who do not wish to continue treatment, or who have reached their ceiling of care, will also have life-supporting measures withdrawn.

These groups of patients are already managed with little controversy by conventional clinical and ethical decision-making processes and do not need to be subjected to the processes of triage.

For those seriously ill patients who opt to receive intensive treatment and for whom intensive treatment is deemed appropriate, usual clinical care in Australia would be to commence, or continue, such treatment. However, when ICU bed supply (or any other treatment modality or venue) is not sufficient to meet demand, it becomes necessary to activate the pandemic triage protocol and engage in the potentially very difficult clinical decision-making that requires exclusionary choices of resource allocation. The details of resource allocation and the ethical foundations of the pandemic triage protocols that may become necessary where resource demand begins to outstrip supply are discussed in the subsequent sections.

All clinicians and the community at large should understand how the variety of patients are managed as they experience their individual illness journeys through the healthcare system. This is likely to be particularly important for clinicians providing palliative care to those patients and their families who are dealing with both impending death and the knowledge that the patient had been denied potentially life-saving treatment. Once such decisions have been made, either through usual clinical decision-making or where pandemic triage protocols have been enacted, these patients who will not receive intensive treatment should receive the best possible supportive and palliative care.

16. *Good Medical Practice: a code of conduct for Australian doctors*, Australian Medical Council, 2014 <https://www.medicalboard.gov.au/Codes-Guidelines-Policies/Code-of-conduct.aspx>

Advance Care Planning

Advance Care Planning has become core business in the complex therapeutic environment of 21st century healthcare in the developed world. Over a period of little more than a century, we have developed a scientific understanding of how our bodies work and how they fail. And in parallel, we have developed a suite of technologies based on an understanding of chemistry, physics and biology that can sustain our lives when we are unwell to an extent that was unimaginable in the late 19th century. As the 20th century wound up, we realised that the success of modern therapeutics is taking many people to a point in their life that the advantages of life-prolongation start to clash with the realities of their inexorable decline in old age, or in some cases diseases that cause decline before older age. For some, the diminishing quality of their life is exacerbated by the burden of their treatment and they may prefer to withdraw from further interventions, new or continuing, that have the goal of prolonging their life.

ACP is a process that supports people to make choices about which of the treatments that are available to them they will or will not accept based on their values, goals and preferences. Although the default position is to act to prevent someone from dying, it should not be presumed that this is the person's wish. ACP is founded on candid, honest and open discussions between clinicians and their patients about the nature of any existing illnesses, their future course and the balance of benefits and harms from possible future treatments. It is based on the principle that people who have the capacity to make the necessary decisions have the right to choose the healthcare that they will or will not accept. For those who do not have such capacity themselves, their legally appointed substitute decision-maker must act in that person's interests and in line with their wishes if previously expressed and/or documented.

ACP is best done before it is needed so that a person has the time to carefully consider their goals and preferences and communicate them both verbally and in writing so that they can be understood by family and clinicians. ACP derived wishes and documents should be available to relevant family and lodged in the medical record for access by clinicians. Though conventional practice in our society in non-pandemic times, some clinicians may find that through lack of training they have not been equipped with the necessary skills and/or find themselves personally overwhelmed by the thought of engaging with patients to discuss confronting issues during difficult times.

During the COVID-19 pandemic, it has become very clear in the US and UK that early ACP has been a vital component of the management of the numerous patients with complex co-morbidities who have become ill with the coronavirus. ACP has meant that patients have been able to refuse unwanted treatment of low benefit, and that may well have caused them significant harm. Those patients who have refused particular treatments have, nonetheless, continued to receive all care and treatment up to their agreed ceiling of care and many have managed to survive even a severe infection with COVID-19.

ACP should never be conflated with discussions about the lack of sufficient resources to treat all those people who it is believed would benefit and desire treatment.

See Advance Care Planning Australia for further information and links to state and national documents for ACP.¹⁷

17. <https://www.advancecareplanning.org.au>

Resource allocation, rationing and triage

The literature on clinical and ethical decision-making in the context of pandemics or disasters has grown rapidly over recent months, with most authors feeling the need to assert their opinion on ethical matters from within the frame of reference of their own particular world view and belief system. Ethics are the absolute and permanent rules that we make up to govern our behaviour and that we adapt according to circumstance. There are, however, a lesser number of common themes around ethical principles, the context of local laws and culture, and some variety in the use of the different terms. The documents that have been reviewed use a variety of terms – resource allocation, rationing, triage – to describe the processes by which finite resources are allocated and distributed, but not always with the same meanings.

We have applied the following meanings to these words in the context of a disaster or pandemic:

- » **Resource allocation** – the whole of the processes by which finite resources are shared and distributed to individuals, organisations and communities according to need and governed by ethical principles.
- » **Rationing** – a system for allocating and distributing a limited amount of a necessity to each person when there is not enough for everyone to have as much as they believe they need – for example, each customer can purchase only one packet of toilet rolls, or the quantity of Personal Protective Equipment (PPE) to be distributed to various types of healthcare providers. Rationing will be experienced by the individual in terms of the proportion of their needs that will be met. The word is derived from the Latin word 'ratio'. We do not include within rationing the process of deciding which person will receive the whole of something and which will receive nothing.

- » **Triage** – a system for deciding the priority of who will and will not receive a particular medical treatment at any given point in time – for example, who will be treated first after a car crash; which person will receive a specific heart or kidney transplant; and which person or persons will be allocated ventilators when there are more suitable candidates than available ventilators. Triage is generally a binary choice between all or nothing, and will be experienced by the individual patient as being either offered or refused a particular treatment at a given point in time.

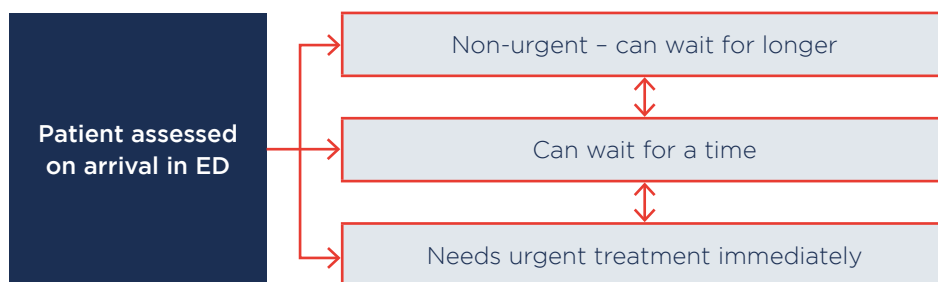
This paper addresses the issues of triage and will not explore the other aspects of resource allocation which are based more on equity, are generally administrative in nature, and do not involve binary choices of exclusion.

Triage is also a term that is used to describe the process of patient prioritisation for treatment in a variety of contexts. Its most common use in everyday practice is in the Emergency Department (ED).

Routine Triage in the Emergency Department (see *Figure 2*)

Day-to-day triage in ED bears little resemblance to the triage first described for sorting the casualties of battle at the time of Napoleon.¹⁸ Patients who arrive in ED are categorised by the urgency and severity of their problems, are reassessed regularly as they wait and can be re-categorised as appropriate. All patients will be treated according to their needs and there is no thought of excluding any person from receiving the most appropriate curative care, or palliative care where applicable.

Figure 2: Routine triage in the ED



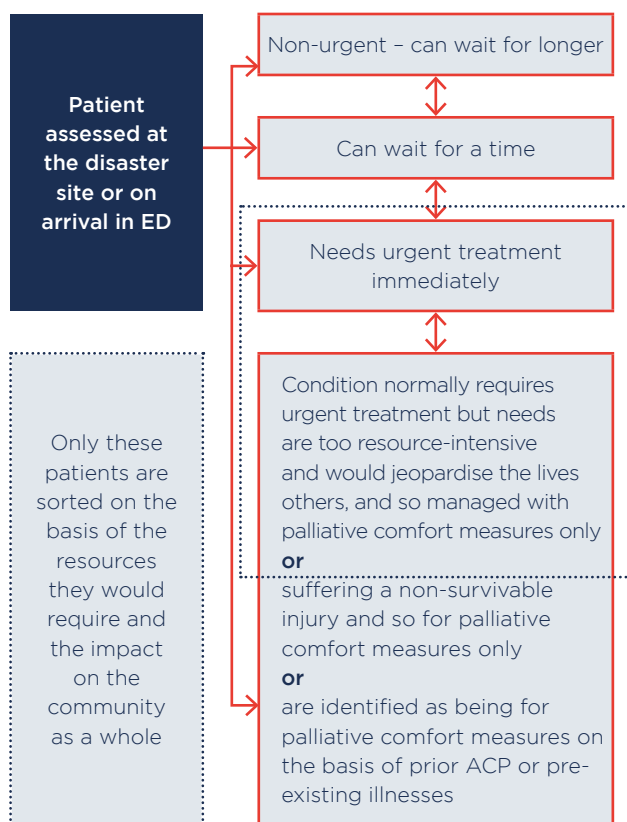
18. <https://en.wikipedia.org/wiki/Triage>

Triage in a localised short-term disaster (see Figure 3)

In the early phases of a major localised disaster, most commonly an unexpected event of initially unknown magnitude, the focus is on maximising the number of people who can survive the disaster.^{19,20} Patients are categorised according to the urgency of their need for treatment, the severity of their injuries and the quantity of resources that would be required for their care. Generally, the expectation is that at some point additional resources will arrive and the triage process can revert to be similar to routine triage in ED. Alternatively, the scale of the disaster may continue to expand and the shortfall in supply may be greater than first thought.

In places with an effective palliative care system, such as many Australian cities, those patients who are identified as having non-survivable injuries can be managed with palliative care. In some places they are admitted to a non-survivable injuries unit that has been created as part of the organisational disaster response plan, and where the goal is supportive and palliative care.²¹ Patients are assessed regularly and may be re-categorised if the balance between the demand and the supply of resources changes in either direction, or their condition improves or deteriorates.

Figure 3: Triage in a localised disaster

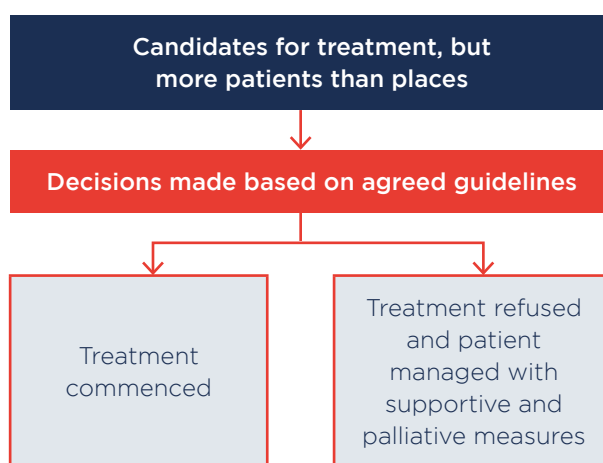


Triage in a pandemic (see Figure 4)

Pandemics are inevitable and extensive preparations, including planning for triage, can be made in the knowledge that a pandemic will occur, but not when it will occur. Such events require a different triage response specific for the particular challenges posed for healthcare services that may be overwhelmed. This is likely to include ethically-challenging triage decisions. While the likelihood that triage will be implemented may not be determined with any accuracy at the outset of a particular event, preparation for triage, including the development of clear guidelines for decision-making, should be undertaken in the absence of a pandemic. Planning should encompass worst-case scenarios while acknowledging that they may not eventuate in every pandemic.

Additionally, the pre-existing workload of expensive high-tech healthcare for seriously ill people will continue and must be integrated into overall planning, including for triage. This is to ensure that the balance of ethical requirements for equity, autonomy and distributive justice continues in the face of competing demands for both human and financial resources.

Figure 4: Triage in a pandemic



19. Queensland Health, *Queensland Health Mass Casualty Incident Plan 2016*, https://www.health.qld.gov.au/__data/assets/pdf_file/0025/628270/mass-casualty-incident-plan.pdf

20. Australasian College for Emergency Medicine, *Curriculum Framework*, https://acem.org.au/getmedia/fae9de05-e9c2-40d3-bee9-be1e66b3b84f/ACF440_0-5.aspx

21. See Townsville Local Disaster Management Group, *Townsville Local Disaster Management Plan, 2019*, https://www.townsville.qld.gov.au/__data/assets/pdf_file/0017/6704/Townsville-Local-Disaster-Management-Plan-April-2019-Public-Version.pdf

A variety of complicating factors found in both the behaviour of pandemic organisms in the population and human response to pandemics change the projected outcome continuously:

- » Pandemics generally start and progress relatively slowly at first, allowing time for further planning and preparation in response to the accumulation of information and understanding (assuming that a pandemic is identified and acknowledged).
- » The severity of a pandemic can be mitigated by behavioural changes. However, the success of such measures cannot be guaranteed due to a variety of factors including:
 - the nature of the organism (virulence and transmissibility) and whether it evolves over time;
 - the variability of human behaviour and our responses to threat and fear;
 - pre-existing cultural norms and cultural cohesiveness;
 - the quality of leadership;
 - the degree of affluence and inequality;
 - the pre-existing health of the community; and
 - the characteristics of the natural and built environments in which the population lives.
- » Nationwide and global spread means that excess demand cannot be met simply by the redistribution of surplus resources.
- » The risks of a pandemic for healthcare workers influences their behaviour, availability and how they are able to treat patients.
- » A failure to support and prepare healthcare workers for the clinical decisions that they must make on behalf of the state can generate moral distress and poses a risk to their mental health. It also poses the risk of state liability for any failure to address in advance the workplace health and safety risks that cause harm to clinicians. For a pandemic, these could range from insufficient PPE to a failure to prepare and provide sufficient guidance and support for clinicians who must make difficult triage decisions.

The flow of pandemic patients during a pandemic has been described in *Figure 1*. So long as resources are sufficient, the healthcare of patients with other illnesses does not require ethically-challenging pandemic triage decision-making. The needs of these patients can continue to be met, although perhaps somewhat differently, and some less ill patients who would previously have been admitted to hospital may be diverted to other places for care where their needs can still be met.

If other measures such as ACP, identification, isolation and social distancing can contribute to a reduction in the case load, hospitals may be able to continue to manage demand without the need to compromise the care of any of those who are candidates for intensive treatment.

However, if the supply of best practice intensive treatment cannot meet the demand for all of those with the pandemic illness and other illnesses requiring intensive treatment, decisions will need to be made on how to:

- » compromise the quality/quantity of care that is provided to all
- » refuse treatment to some so that others can have best practice treatment
- » cease the provision altogether of some intensive treatments which have a low success rate, or
- » a combination the above.

In practice this means withholding or withdrawing potentially life-sustaining treatment from some patients.

There may be times when the demand and/or the capacity for intensive therapy decrease or increase significantly. In the event of a net improvement, it may be possible for triage decision-makers to recategorise patients who had previously been refused treatment to now receive such treatment. Equally, if the situation deteriorates, all patients who are candidates for intensive treatment, including those for whom such treatment has already been commenced, may be reassessed according to accepted guidelines and established treatment withdrawn from some patients. The harsh realities of such necessities can be very challenging for all concerned.

It is easy to draw the diagram that visualises the flow of patients, or to use words to describe the pathways. But neither determines the grounds – the principles and the values – on which the community agrees we should make decisions that deny treatment to some, including perhaps even to ourselves and/or members of our family. These principles, and the clear guidance which must stem from them, are essential in planning for pandemic triage decision-making.

Pandemic triage decision-making and the principles of ethics

Like most communities, Australia would prefer to be seen as a nation that does not countenance discrimination in any form. But like others, our community is imperfect, with bias and discrimination evident in many walks of life. We have a variety of laws that try to prevent discrimination, and a variety of standards and codes of conduct that endeavour to support non-discriminatory behaviour.

Most people generally deplore the idea that healthcare decision-making would be based on race, gender, age, frailty, overall health, life-expectancy, perceived social worth, or any other variables. However, in the context of an overwhelming pandemic when the number of patients who would benefit from treatment is greater than the number of places available, it becomes impossible to avoid having to find some criteria by which to choose which people to treat.

A variety of organisations have created high-level documents that provide a framework for the creation of decision-making guidelines based on key ethical principles.^{22,23} Whatever ethical framework is used to create guidelines for refusing treatment for some people and not others, such binary decisions about resource allocation in times of inadequate supply are, by definition, discriminatory in the broad sense of the word. They authorise clinicians, when faced with a group of patients who would normally receive treatment, to identify differences between individuals, or groups of individuals, on which to base decisions as to who will receive treatment and who will not.

Such decisions generally run counter to the ethical values and principles by which clinicians normally make clinical decisions based on individual patient autonomy, beneficence, justice, non-maleficence and our duty of care to act in each of our patient's best interests. Most clinicians accept that it is good medical practice to make hard but wise decisions about individual patients based on their medical realities and the balance between the likelihoods of

delivering benefit and causing harm (including not offering futile treatment), and to defer to individual patient wishes on the choices that are open to them. Clinical training generally prepares clinicians for such actions, and they are supported by codes of conduct. However, no amount of training can prepare clinicians to make unsupported, unilateral or discriminatory choices necessitated by shortages of supply that clash with the core principle of promoting the interests of each of their individual patients.

The framework for pandemic triage decision-making must be founded on and justified by clear ethical and clinical standards, and then supported by unambiguous frameworks for making difficult decisions. If faced with the decision not to treat some people because of resource scarcity, the challenge is to find the grounds that are the least unacceptable to the community.

There are a range of options for ethical standard setting across the spectrum from clinical bioethics (the duty to the individual patient) to population-level bioethics (the duty to the broader population).²⁴ The weight given to any particular ethical principle may vary across the range of options as decision-makers seek to deal with the specific challenges of shifting needs and resources over the life of a pandemic.^{25, 26, 27, 28}

The following principles are at the core of most current and emerging guidelines demonstrating a growing sense of agreement:

Best use of resources and stewardship

In the context of a pandemic, the aim is to use the available but limited resources that, while insufficient to treat all people who might benefit, will bring maximal benefit to the greatest number of people – the greatest good for both individual patients and the population of individuals. The designers of a system of triage are accepting

-
22. National COVID-19 Health and Research Advisory Committee. *Ethical issues arising from the COVID-19 pandemic*, Australian Government National Health and Medical Research Council, 12 May 2020, <https://www.nhmrc.gov.au/file/15357/download?token=OVb1YcC->
 23. World Health Organisation. *Guidance for managing ethical issues in infectious disease outbreaks*, WHO, Geneva, 2016, <https://apps.who.int/iris/bitstream/handle/10665/250580/9789241549837-eng.pdf?sequence=1&isAllowed=y>
 24. Wynne KJ., Petrova M. and Coghlan R. Dying individuals and suffering populations: applying a population-level bioethics lens to palliative care in humanitarian contexts: before, during and after the COVID-19 pandemic. *Journal of Medical Ethics*, Published Online First: 19 June 2020. doi: 10.1136/medethics-2019-105943
 25. Emanuel EJ., et al. Fair allocation of scarce medical resources in the time of COVID-19, *New England Journal of Medicine*, 2020, <https://scts.org/wp-content/uploads/2020/03/Fair-allocation-of-medical-resources-NEJM-23rd-March-2020.pdf>
 26. Veterans Health Administration's National Center for Ethics in Health Care. *Meeting the challenge of pandemic influenza: ethical guidance for leaders and healthcare professionals in the Veterans Health Administration*, USA, 2010.
 27. New York State Task Force on Life and Law, *Allocation of ventilators in an influenza pandemic*, New York State Department of Health, New York, 2015.
 28. Savulescu J. and Wilkinson D. Who gets the ventilator in the coronavirus pandemic? These are the ethical approaches to allocating medical care, *ABC News*, 18 March 2020 <https://www.abc.net.au/news/2020-03-18/ethics-of-medical-care-ventilator-in-the-coronavirus-pandemic/12063536>

responsibility to provide both guidance and instruction, and moral support and validation to clinicians who are having to choose which patients will receive a particular treatment and which will not. Writing that was the easy part.

The method for assessing whether resources have been used to best effect can be understood in a variety of different ways. The most obvious measures are quantitative. The simplest would be to maximise the absolute number (quantity) of people who are prevented from dying. A straightforward variation of this goal would be to try to maximise the quantity of years of life saved – i.e. a person who was expected to live for 20 years would rate higher than another whose life expectancy was two years.

Another alternative way of fulfilling this goal is to put a premium on the opportunity provided by preventing a death. Those who have not yet had the same opportunity to experience a full life with further weighting for an assessment of the quality of the life that the survivor is likely to experience.

A further factor often considered is the subjective measure of the likely quality of the life that could be lived by a person who is enabled to survive the pandemic by a particular treatment.

Frequently, the factors above converge in a tendency to deny treatment to the elderly who are most likely to have a short life-expectancy and multiple factors that reduce their quality of life.

Other models have included the influence that the survival of a particular individual might have on the lives of others. For example, one community in an impoverished area of the world had the standing ICU admission policy that it would admit only male bread-winners and if they were not improving after 48 hours they would be discharged to die.²⁹ This was based on the utilitarian premise that, where the demand for ICU beds was always greater than the supply, the consequences of the death of the male breadwinner would play out most significantly in the lives of his multiple dependents.

There is a growing agreement that the maxim of saving the greatest number of lives is not complete without an ethical principle which also balances respecting the rights and needs of the individual patient. The best use of resources principle has also frequently ignored those resources specific to vulnerable or minority groups.

And confounding all these is that a specific decision to provide treatment to one person with the intention of minimising discrimination may deny the opportunity to several people with lesser needs. These ethical conflicts cannot be resolved by the individual clinician at the bedside.

The translation of the principle of responsible stewardship of resources into a practical system for decision-making triage depends on transparent and public development processes that openly acknowledge conflicts between ethical principles cannot make non-discriminatory what is essentially a discriminatory process.

Duty of care and the principle of non-abandonment

These encompass the norms of medical ethics and clinical decision-making. Systems for pandemic triage and resource allocation cannot disregard the fundamental obligation of health providers to care for their patients. The principle of non-abandonment means that clinicians have an ethical duty to continue to provide care to the best of their ability with the resources available to individual patients, and a duty to endeavour to bring benefit and prevent harm to individual patients. This principle respects the rights and needs of individuals without consideration of the broader population.

Clinicians have an enduring duty of care to their patients who are triaged not to receive ICU or ventilatory support because of resource limitations during a pandemic, and are required to continue to provide them with other available forms of medical support and/or palliative care. All patients should receive the best possible care under crisis conditions, including palliative care, whether or not they are diagnosed with COVID-19 and whether or not they are allocated an ICU bed or a ventilator if indicated.

The demands of a pandemic triage system compromise the ability to uphold individual autonomy in a pandemic, but do not negate the requirement to provide patients with the necessary appropriate alternative forms of care where potentially life-prolonging treatment is not available to them.

29. Cairns W. Verbal presentation by a doctor from southern Africa visiting Townsville in - 1980

Equal value (non-discrimination and fairness)

Triage guidelines should be structured to minimise the risk of discrimination and bias. It is commonly agreed that each person is of equal value and deserving of equal respect. While pandemic triage is by its nature discriminatory, it is generally accepted that resources should not be allocated on the basis of criteria such as ethnicity, gender, disability, social worth or wealth, religious or political views, sexuality, etc. It is also mostly agreed that age alone should not be used as the criteria for resource allocation – this would be blatantly ageist. Resources may, however, be allocated instead on other patient characteristics such as capacity to benefit, prognosis and time to benefit – a variety of clinical scales and scoring systems have been developed to determine quantification of such judgements.

There also should be no difference in allocating scarce resources between patients with COVID-19 and those with other medical conditions. Fair allocation of resources applies across all patients who need critical care, although it can be very challenging to weigh up the relative priority of patients with very different conditions and needs.

Justice

Distributive justice refers to a system of triage that is applied consistently between individuals, across hospitals, public or private, and across states. The allocation of critical and scarce resources must consider the size and needs of local populations and supplement resources accordingly. Adherence to the principles of distributive justice can ensure that responses to the pandemic do not exacerbate existing inequalities in access to healthcare, and that resources are allocated appropriately for vulnerable communities and populations who may suffer the greatest impacts of the crisis. On a practical level, the realities of disease distribution, geography and transportation may mean that distributive justice may not be easy to sustain even within a single geopolitical community.

Adhering to the principle of justice requires leadership and coordination from State-based and Federal governments.

Ethical principles and palliative care

There are different ways of balancing the principle of best use of resources, whilst respecting the values of each individual human life through duty of care and justice. This is summed up in the CDC's Ethical Guidelines in Pandemic Influenza which state that:

“a classic utilitarian approach to defining priorities (...) is not a morally adequate platform for pandemic influenza planning. We recommend (...) an approach to ethical justification, that, like utilitarianism, evaluates the rightness or wrongness of actions or policies primarily by their consequences, but (...) that planning should take into account other checks (...) grounded in the ethical principles of respect for persons, nonmaleficence, and justice.”³⁰

This balancing act is at the core of the ethical tension in pandemic triage and the reason why so many documents discuss ethical principles, but stop short of developing specific tools for decision-making. As the number of infected patients increases and available resources decrease, these decisions become more and more challenging and potentially distressing. At the same time, the increasing gravity of the situation also helps an informed community to accept the need for such decision making.³¹

A strictly utilitarian approach which adheres to the best use of resources principle may seem to justify concentrating all health resources on those lives that can be saved. However, the best interests of the community and common humanity are also best served by an approach which balances duty of care, non-abandonment, fairness, justice and human dignity, and requires that patients who are suffering and/or are not expected to survive will be provided with the highest possible quality of symptom management and palliative care. Any decision-making guidelines must include the expectation that all patients will continue to receive the best available care even when curative treatment cannot be provided. Most clinicians will understand their ethical duty never to abandon a patient who is dying and to do their best to provide appropriate care.

30. Kinlaw K. and Levine R. *Ethical guidelines in pandemic influenza. A Report of the Ethics Subcommittee of the Advisory Committee to the Director, Centers for Disease Control and Prevention.* 15 February 2007.

31. Ouyang H. I'm an ER doctor in New York. None of us will ever be the same, *New York Times*, 14 April 2020, <https://www.nytimes.com/2020/04/14/magazine/coronavirus-er-doctor-diary-new-york-city.html?referringSource=articleShare>

Turning ethical principles into practice

Ethical principles are useful guides when dealing with moral dilemmas, but they do not instantly solve every problem and in some situations can be in conflict. A principle-based system of ethics is necessary but not sufficient for the ethical challenges posed by severe resource limitations in a pandemic. The above principles tell us what is good to do, but not which good takes priority or how we should act when it becomes necessary to engage in pandemic triage.

Many of the pandemic or disaster triage related documents currently produced by governments skirt around that most difficult of challenges – stating how to choose which people will be offered treatment, and which will not, when the number who would benefit is larger than the number who can be treated (see *Appendix A*). Ethical principles are discussed but clear decision-making frameworks are seldom included, particularly in jurisdictions where the cultural memory of the necessity for challenging triage decisions amidst resource-scarcity has faded, or where few have had the real-life experience of facing such challenges; guidance documents have commonly been based on hypothetical scenarios.

Patient advocacy groups generally recognise that discriminatory decisions must be made. However, understandably, they generally state that discrimination should not be undertaken solely on the basis of being a member of the group for which they are advocating.

A large proportion of the balance of documents that are produced by theoreticians, academics, ethicists and some clinicians are explicit in stating that the responsibility for determining the basis for such triage decisions rests, not with the clinicians caring for individual patients, but with governments, and that governments should accept legal responsibility for the consequences of triage for individual patients. However, most government documents do not clearly describe the basis on which clinicians at the bedside would make pandemic triage choices.

So, how should Australian healthcare settings turn these ethical principles into practice in the event of severe shortages of critical care and when pandemic triage becomes necessary? Various allocation methods have been proposed.

Those most commonly discussed are included here. We are not expressing a preference because accountability for making, communicating and owning decisions on the content of pandemic triage is a duty of government in open collaboration with its community.³²

Egalitarianism (*first come, first served, or lottery*) approach

The egalitarianism approach of ‘first come, first served’ argues for equality of access – everyone should have an equal chance of treatment when there are equally pressing needs and no factors should be used to discriminate between patients. This is the stated principle of health services under usual practice.³³

Lottery, or random allocation, is another approach of equality of access similar to the first come, first served method.³⁴ This approach implies that doctors should flip a coin to decide which of two patients with equally pressing needs should receive the ventilator or ICU bed.

Utilitarianism (*best use of resources*) approach

The utilitarianism approach is based on the best use of resources and stewardship principles described above, with doctors choosing the actions which bring about the most good for the greatest number of people, in the context of limited resources. As discussed, this approach involves judgements about chances of survival and quality of life and can be seen as highly controversial.³⁵ It is also the approach deemed most useful and morally just in emergency triage where clear, transparent, ethical and accountable clinical decision-making frameworks are developed.³⁶

Contractualism, which asks doctors to make choices behind a ‘veil of ignorance’, roughly converges with utilitarianism.³⁷

32. Cairns W. and Coghlan R. 2020

33. Savulescu J. and Wilkinson D. 2020.

34. Emanuel EJ., et al. 2020.

35. Savulescu J. and Wilkinson D. 2020.

36. Emanuel EJ., et al. 2020.

37. Savulescu J. and Wilkinson D. 2020.

Paternalism and the myth of ‘the greater harm’

Doctors may rightfully argue that it is harmful to ventilate some older people or those with a poorer prognosis, and that they are fulfilling their duty of care to a patient by refusing to provide a harmful treatment. But in some cases this may be a paternalistic value judgement – where a ventilator holds some chance of saving a person’s life and that resource is available, the patient, or their decision-maker, needs to be involved in the decision to proceed or forego the treatment.³⁸ The greater harm justification may also be used to disguise, even by the doctor from him or herself, the reality that a necessary triage decision is being made because of a scarcity of resources.

Prioritising particular groups

Different decision-making frameworks discuss the need to prioritise particular groups. Some argue for prioritisation of healthcare workers who hold instrumental value in re-joining the workforce to tackle COVID-19 once they are well again.³⁹ There is some discussion that they may be particularly useful if they then have immunity against COVID-19, although the extent of COVID-19 antibody protection after exposure is currently a subject of debate. If a healthcare worker has been so unwell as to require ventilator support, it is also doubtful that they would be able to contribute meaningfully or be of utility in the course of the pandemic. Others have suggested that in the context of COVID-19, healthcare workers should be favoured in compensation for the added risk for themselves and their families that they have taken in providing care for patients.⁴⁰

Some are also arguing for the prioritisation of vulnerable groups; for example, pregnant women,⁴¹ those most disadvantaged because of structural health inequities, those at increased risk of harm, and those we know have suffered injustice in the past.⁴² One recent article describes the inherent bias in current frameworks of ventilator rationing against groups with lower socioeconomic status, particularly people with disabilities or particular ethnic groups – not through overt discrimination but because of clinical markers and poorer health

status and outcomes – and argues for a fairness weighting system.⁴³

In Australia, some have suggested the need for prioritisation of Aboriginal or Torres Strait Islander populations who have poorer social determinants of health caused by structural and historical inequities and past injustices.⁴⁴

Whatever criteria are chosen, they must be applied consistently within and across healthcare settings. It is also essential to ensure that patients and communities are involved in, and understand, decision-making processes. Such operational principles are outlined in *Taking Responsibility* below. Humanitarian Hugo Slim writes that such triage systems in the context of resource-limited humanitarian settings “*seem to make painful but genuine moral sense to those involved – carer and patients alike*”.⁴⁵ With transparent, ethical and participatory processes, we shouldn’t be so fearful of taking the plunge.

As Savulescu and Wilkinson recently wrote:⁴⁶

“Unavoidably, there will be winners and losers. We have to take responsibility for making those decisions as ethically as possible”.

38. *ibid.*

39. Kirkpatrick DD, and Mueller B. UK Backs off medical rationing plan as coronavirus rages, *New York Times*, 3 April 2020, <https://www.nytimes.com/2020/04/03/world/europe/britain-coronavirus-triage.html?referringSource=articleShare>

40. Fink S. The hardest questions doctors may face: who will be saved? Who won’t? *New York Times*, 21 March 2020, updated 31 March 2020, <https://www.nytimes.com/2020/03/21/us/coronavirus-medical-rationing.html?referringSource=articleShare>

41. Daugherty Biddison EL., et al. Too many patients...a framework to guide statewide allocation of scarce mechanical ventilation during disasters. *Chest*, Vol.155(4), pp.848-854, 2019

42. University of Sydney. *An ethics framework for making resource allocation decisions within clinical care: responding to COVID-19*, Sydney, April 2020, <https://www.sydney.edu.au/content/dam/corporate/documents/faculty-of-medicine-and-health/research/centres-institutes-groups/she.-clinical-ethics.-resource-allocation-framework.-version-1.-2-april-2020.pdf>

43. Schmidt H. The way we ration ventilators is biased, *New York Times*, 15 April 2020, <https://www.nytimes.com/2020/04/15/opinion/covid-ventilator-rationing-blacks.html?referringSource=articleShare>

44. University of Sydney, 2020.

45. Slim H. *Humanitarian ethics: a guide to the morality of aid in war and disaster*, Hurst and Company, London, 2015

46. Savulescu J. and Wilkinson D. 2020.

Taking responsibility

The most important feature of planning for pandemic triage is that the documents that describe the criteria for decision-making by clinicians must be designed by clinicians, their community and government, and supported in practice and in law by government.

Clinicians who undertake the onerous duty of pandemic triage on behalf of, and in the interests of, their community must know that their government supports them, understands the gravity of the choices that they must make, and provides them with the legal authority to do so. Without such guarantees, clinicians are on their own. Clear instruction from government relieves a huge burden of individual responsibility from clinicians who can focus on providing good clinical care while receiving the overt support of the state when binary decisions about refusing potentially life-saving treatment are necessary.

Patients and their families must know that, when clinicians make these most serious of triage decisions, they are following guidelines that have been accepted and supported by government in the interests of the community as a whole.

The process of determining the grounds for binary decisions about the allocation of resources like ventilators in ICU requires an open and candid conversation with the community in order to reach a consensus view. Our leaders have a responsibility to act on our behalf by leading the community engagement necessary to consolidate our views and to document and implement the outcome. This difficult task is a responsibility with which we honour them by electing them.

A failure to engage in the creation of a guiding framework for pandemic triage in a timely manner would be an abdication of the duty of government. Patients would face the risk of uncertain and variable decision-making. Clinicians risk the moral distress of having to make choices with no certainty that they are acting with the support of their community, and that their actions may clash with the very core of their moral values and the sense of who they are as clinicians.⁴⁷

Summarising what has been discussed above, there are a number of key principles which emerge from the literature for the design and implementation of pandemic triage decision-making processes. Guidelines that are developed

without concern for, or adherence to, these core principles risk deepening the moral distress of clinicians, patients and communities when challenging triage decisions must be made.

- » **The duty of governments and policymakers.**
Governments have a duty to lead the creation of triage decision-making guidelines and to take responsibility for triage decision-making criteria and the consequences of their implementation. This ensures a clear, non-biased and legally defensible process that relieves the burden of responsibility from individual clinicians who can then focus on providing good clinical care. Government-led processes also ensure that triage decisions can be implemented consistently across hospitals and other clinical care settings within distinct geopolitical areas.
- » **The importance of community voice in developing triage guidelines.**
The process of determining triage decisions requires the genuine participation of the communities who will be affected by these decisions. Governments have a responsibility to lead community engagement in a candid and open manner that reflects the gravity of the matters that are being discussed. The community's voice must be acknowledged and represented in the guidelines. A genuine partnership with communities also means they should be involved in feedback mechanisms and guideline review processes.⁴⁸
- » **The role of hospital triage committees to support ethical decision-making.**
Ethical decision-making groups such as hospital triage committees are necessary to support the implementation and monitoring of government guidelines. These groups can help ensure consistent and transparent decisions on resource allocation, provide impartial and neutral support to clinicians where there is ambiguity or uncertainty, and ensure clinicians do not feel the burden of making decisions alone.⁴⁹
- » **The need for dynamic review processes.**
While unambiguous and ethical pandemic triage decision-making may be based on sophisticated metrics or scoring systems, the process of implementation must allow for regular clinical review to ensure optimal use of resources. The clinical state of patients must be assessed

47. See Fink S. The Deadly Choices at Memorial. *New York Times*, 25 August 2009. <https://archive.nytimes.com/www.nytimes.com/2009/08/30/magazine/30doctors.html>

48. For example, see the World Health Organisation definition of participation: <https://www.who.int/gender-equity-rights/understanding/participation-definition/en/>

49. Rogers W. and Carter S. *Ethical considerations regarding allocation of ventilators/ICU beds during pandemic associated scarcity*, University of Wollongong, Australia, 2020. <https://documents.uow.edu.au/content/groups/public/@web/@socs/documents/doc/uow264048.pdf>

frequently to determine whether their care needs and triage status have changed. The availability of resources must be monitored and compared with the demand so that triage implementation can be adjusted to most effectively distribute the supply of available treatment to meet patient demand.

» **Consistency in the implementation of triage guidelines.**

To ensure equitable decision-making, guidelines need to be implemented consistently across hospitals and across States and Territories.⁵⁰ In Australia, this means that, while guidelines must meet State and Territory legal requirements and practical realities, they should also be as similar as possible reflecting our unity as a nation (“We are one, but we are many”⁵¹).

» **Transparency in triage decisions.**

Guidelines and decision-making processes must be candid, compassionate, open and accessible to healthcare staff, patients, families and communities. Having participated in the genuine and broadly inclusive development of guidelines that are transparent and publicised, communities and clinicians will be in a better position to understand and ultimately accept the moral basis of the decisions that must be made, no matter how painful.⁵²

» **Accountable processes.**

Governments must be accountable to clinicians and communities for the development and review of triage guidelines. Those responsible for ensuring the implementation and monitoring of Guidelines need to be identified, for example, triage committees. Guidelines should include processes for appeals and dispute resolution.⁵³ Guidelines are living documents and reviewed regularly as new information (such as evidence of prognostic factors and new treatments) emerge over the course of the pandemic.

» **Ensuring ongoing personal and supportive care irrespective of triage decisions.**

Triage guidelines must include details of the care patients will receive when they are refused access to ventilators and intensive care. Even when such intensive potentially life-prolonging treatments are not available, appropriate supportive interventions, such as antibiotics, patient positioning, oxygen therapy and chest physiotherapy, can significantly reduce mortality and suffering from COVID-19 and should not be forgotten. Fundamentally, guidelines need to

mandate high quality symptom management and palliative care. Triage protocols must not stop at the binary decisions concerning who and who does not get the ventilator, but extend to support decisions around determining the most appropriate form of care will provide the best for each individual patient with the resources available.

Writing in *The New York Times*, economist Thomas Friedman and his friend Dov Seidman reflect on the importance of leadership in the COVID-19 pandemic:⁵⁴

“Great leaders trust people with the truth. And they make hard decisions guided by values and principles, not just politics, popularity or short-term profits. Great leaders understand that when so many vulnerable and scared people are so willing, so quickly, to put their livelihoods and even their lives in their leaders’ hands, and make sacrifices asked of them, they expect the truth and nothing but the truth in return. Leaders who trust people with the truth are trusted more in return. But you better not betray my trust — by not telling me the truth — when I have literally put my life in your hands.”

The leadership of our State/Territory and Federal governments and their capacity to speak truth and earn the trust of citizens has never been more important. Such trust can be enhanced when leaders admit that they do not have all the answers, demonstrate humility, and invite communities to collaborate towards a common purpose. Our governments bear responsibility to lead the process and implement decision-making frameworks. Accountability ultimately rests with them. However, they will not have our trust without creating the space for communities to participate and by openly sharing all outcomes, allowing public comment, and permitting public scrutiny and feedback as triage guidelines are enacted.

50. *ibid.*

51. “*I am Australian*” song lyrics, <https://www.abc.net.au/cm/lb/11615032/data/we-are-australian-song-lyrics-data.pdf>, accessed 23 June 2020

52. Rogers W. and Carter S. 2020

53. *ibid.*

54. Friedman T. We need great leadership now, and here’s what it looks like, *New York Times*, 21 April 2020, <https://www.nytimes.com/2020/04/21/opinion/covid-dov-seidman.html?searchResultPosition=10>

Dealing with the hazards, burdens and distress of pandemic triage

Most of us accept rationing as a necessity based on a sense of fairness and community interest in the event of shortage. Of course, this also provides the reward of the very positive sense of belonging to a community that shares the burden of privation somewhat equally and is reinforced by strong societal disapproval of hoarding and exceptionalism.

*One physician told me, "I know a doctor in town who was asked to go to someone's property once the private ventilator arrived, to make sure it was operational." Disturbed by this hoarding of medical supplies, this person said, the doctor refused.*⁵⁵

The realities of exclusionary triage are another matter. While few deny that there are circumstances in which such actions are necessary, no-one likes the idea that they might have to participate in the process, whether as subjects, implementers or as those who must set the parameters that will govern the process.

When triage is necessary, we have little choice but to compromise the core ethical principles (the values and derived rules) that we profess to agree on to guide our behaviour. This is a huge challenge for all members of the community as it tests the ways that we view ourselves, our roles, our humanity, our belief systems and the values that sustain our community at large.

As we contemplate how we might go about designing and implementing the processes for pandemic triage for binary choices it is important to recognise that there are no winners:

- » The leaders who must create and approve systems for triage will have to engage with their community in a frank and honest manner to discuss very difficult issues.
- » Clinicians will be required to decide which patients will not be offered potentially life-saving treatment and then inform and discuss this highly confronting issue with these patients, and the patients' families. They may be required to undertake this task repeatedly with multiple patients.
- » Patients who are refused treatment and who are conscious will have to receive this information,

sometimes when alone and isolated by the demands of infection control.

- » The families of those who have been refused treatment may not have been allowed to visit the patient and may remain unable to visit them as they are dying, or even to see them after they have died. They may be socially isolated by disease, social distancing requirements or simple geography in their grief.
- » Some of the patients who are chosen to receive treatment may also experience survivor guilt as they contemplate their good fortune.
- » The clinicians who must implement triage on a repeated basis face one of the most difficult tasks that can be asked of a clinician – deciding which of their patients not to treat while believing that they would all benefit from such treatment.

It is very clear that the necessary implementation of triage brings with it a number of short and long-term hazards and consequences for all of the participants.

First and foremost is the risk that the community may not accept the process and that conflict may break out because agreement has not been reached on the ethical principles or values that underpin the guidelines, or that they believe that they will not be applied to everyone equally. When discussions start early and are very candid about the gravity of the conditions that would require activation of triage, we are much more likely to accept the necessity for such decision-making and its intrinsic discrimination. In Italy, triage guidelines were initially rejected by many, but those voices fell silent in the face of the harsh realities that emerged.⁵⁶

Clinicians need guidelines with enough lead-time to be able to integrate an understanding of how they should be applied. If they have to make up their own on the spot, they are at risk of severe stress from the clash between the beliefs that define their identity as a health worker and what they are forced to do by the pandemic. This causes severe moral distress that may play out later in their life and their career with potential consequences for them and their families, their

55. Farrell J. Where the very rich fly to hide. *New York Times*, 15 April 2020. <https://www.nytimes.com/2020/04/15/opinion/jackson-hole-coronavirus.html?searchResultPosition=1>

56. Ouyang H. 2020.

healthcare employers and their community.⁵⁷

ED and ICU staff in Italy and in New York, working flat out without prior guidance and with insufficient time to contemplate the ethical balance of rights for every patient, designed their own scoring systems on which they, or in some cases panels of external impartial clinicians, could base on-the-spot decisions.⁵⁸

In Germany, where triage has not been necessary, guidelines are in place should it become so.

“It is important that we have guidelines for doctors on how to practice triage between patients if they have to,” Professor Streeck said. “But I hope we will never need to use them.”⁵⁹

And in Australia there is a growing awareness of the responsibility of governments to prepare for pandemic triage with a clear set of guidelines that are the product of open and public consultation. The Australian and New Zealand Intensive Care Society (ANZICS) stated in its *Guiding principles for complex decision making during Pandemic COVID-19* that:

“ANZICS acknowledges that patients may die as a result of resource scarcity and that this situation may occur even with optimal planning and coordination. It is essential that this is publicly acknowledged, and that health care workers are supported by hospital executives and civil authorities. This support must include protection from legal and other liabilities when they have acted according to relevant endorsed practices, including jurisdictional guidelines. This guideline recognises that accountability for such outcomes extends beyond the individual clinician to include health care organisations, departments of health and government.”⁶⁰

The ANZICS document requires complementary government action. We await the release by the governments of various Australian States and Territories of the necessary documents. These are slowly being developed but many have restricted access as *confidential* and/or *draft* documents awaiting political approval. This would seem to be an anathema for documents that must be open and accessible to fulfil their role. Surely the whole point of pandemic triage documents is that they be explicit so that the community can understand and accept why difficult decisions may need to be made in the event of extreme circumstances, and with the additional benefit of their gravity providing an incentive for compliance with

measures that will reduce the likelihood of their being used.

Another hazard that has arisen in the need to make difficult decisions in the context of COVID-19 is the enforced physical isolation of patients, their families and clinicians from one another by the bans on visiting and the use of dehumanising PPE, together with the rapid turnover and heavy workload. All these have meant that the personal human relationships that are at the core of whole person care have been hugely restricted. All the participants have been cut off from that vital source of spiritual (in the broadest sense of the word) energy that sustains us, the personal engagement with other people that is so necessary for our wellbeing as social animals.

Those of us who have experience in providing care for dying people will know that it is when we form a relationship with our patients based on our common humanity that we are of most help to them. While healthcare technology can make a huge difference to physical symptoms, it is the simple acts of communication – touch, conversation and the building of trust – that help our patients, their families and clinicians to find peace at the end of a person’s life. The demands of infection control and a huge workload of COVID-19 can rob everyone of the opportunity of support to deal with their loss and grief, and to make some sense of what is happening.

As time passes and the pandemic eventually wanes, we will be left with a vast burden of loss, grief, guilt, anger, resentment and stress. Some of these responses will arise from the disruption to lives and the economic consequences of COVID-19, others from the shattering of the sense that some people – those with the strongest sense of agency over the outcomes in their life – may be the most affected, and the disempowered will have their beliefs confirmed.

Many people will carry the social, economic and psychological consequences of this pandemic for the rest of their lives. The sequelae of poverty, social disharmony and psychological stress will play out in the lives of those scarred by COVID-19. And when at some time in the future they find themselves interacting with palliative care services, their responses may well depend on how well they were supported in 2020.

57. Steven Chau, *Who will heal the healers? The psychological aftermath of COVID-19*, BMJ, 2020

58. Ouyang H. 2020.

59. Bennhold K. A German exception? Why the country’s coronavirus death rate is low, New York Times, 4 April 2020, updated May 6 2020, <https://www.nytimes.com/2020/04/04/world/europe/germany-coronavirus-death-rate.html?referringSource=articleShare>

60. Australian and New Zealand Intensive Care Society. *Guiding principles for complex decision making during Pandemic COVID-19*, ANZICS, Melbourne, 2020, https://www.anzics.com.au/wp-content/uploads/2020/04/ANZI_3367_Guiding-Principles.pdf

Open and transparent availability of documents that support wise resource allocation and triage decisions in Australia

Over the course of writing this discussion paper, we have read countless documents on resource allocation. No document has disagreed with the premise that there was, and remains, a possibility that our health services will be overwhelmed by COVID-19, or that as a community we should prepare ourselves to deal with the challenge of resource allocation when available resources do not meet demand.

How well do these documents prepare our community and our healthworkers for the need to make those most difficult choices – which people will be treated should it be necessary to exclude one or more?

Some of the documents were prepared prior to this pandemic, while others were pulled together as part of the rapid response to the looming threat of the coronavirus. Prior documents address the need to prepare early and some are quite comprehensive and practical in the ways that they address the broad range of issues of pandemic planning, including how the criteria for exclusionary decision might be decided (for example *Crisis Standards of Care: A Systems Framework for Catastrophic Disaster Response: Volume 1: Introduction and CSC Framework (2012)* from the US National Academies of Sciences, Engineering and Medicine⁶¹). These tend to address the theoretical foundations of resource allocation without offering any specific practical steps about how it should actually be done.

Many of the documents that have been created since the onset of this pandemic have been very helpful in encouraging ACP to reduce the likelihood that healthcare services providing intensive life-prolonging treatment will be overwhelmed. Few address the possibility that the component of healthcare that does not provide such treatment, palliative care, might also be overwhelmed.

In Australia, almost every jurisdiction has produced at least one document that describes the process for creating guidelines for triage in the event that hard decisions become necessary, including recommendations that:

- » The process should be open and transparent.

- » The documents should be available as public documents before they are needed.
- » The documents should be made available once completed for all clinicians who must prepare to implement them.
- » Governments acknowledge risks of moral distress to healthworkers if they do not have access to state sanctioned criteria for pandemic triage.
- » Governments should create and endorse standardised documents.
- » Governments should indemnify clinicians who apply the guidelines that have been created and endorsed.

Such documents also suggest criteria that might be used for triage in the event that exclusionary triage becomes necessary and discuss the ethical reasons that particular criteria should or should not be included. Several address the need to proceed further for the reasons described above. Some actually refer to a process by which that will be done.

But almost invariably, even though there are faint whispers of ongoing activity in Australia, that is where the trail goes cold. We have been variously told informally that explicit triage guidelines:

- » have been created and will be released only when we need to use them
- » are being or will be considered by Cabinet but are currently a Cabinet secret
- » exist but have gone to the jurisdictional legal department to make sure that they will stand up in court
- » are being held up by the politicians and bureaucrats who are afraid of the community response
- » are in the hands of legal/legislators, or
- » “*Are ready, but we [the team, including the clinicians who created the guidelines] had enough hassle about the pre-guideline document and we didn’t want to face the flack over the guidelines themselves.*”⁶²

61. US Nat. Acad. Sci.Engin.Med. *Crisis Standards of Care: A Systems Framework for Catastrophic Disaster Response: Volume 1: Introduction and CSC Framework (2012)*, The National Academies Press, 2012 <http://nap.edu/13351> ISBN 978-0-309-25346-8 | DOI 10.17226/13351

62. Cairns W. anonymous personal communication

These whispers mirror the withholding of medical rationing guidelines by the UK Government previously reported in the media.⁶³ In summary, it seems the default mode here in Australia and in many other jurisdictions is that clear triage guidelines will be released only if they are needed, but without specifying how long before. Perhaps the Swiss and the Germans are more rational, pragmatic and/or mature. They have produced pandemic triage guidelines that have been released to the community in case they are needed.

We appreciate that this is a complex issue for governments as there are a number of irreconcilable issues that mean there is no avenue that does not involve some risk. However, the experience of palliative care clinicians, as well as countless other healthcare workers and people working across diverse fields from law to engineering, is that keeping information from those who are being or will be affected by it is the riskiest course of all. Secrets create distrust, sow the seeds of fear and deny people the opportunity to deal with the issues that they are facing. In the context of COVID-19, trust is a vital commodity if the community is to engage with the measures that are necessary to contain the pandemic.

All forms of media are replete with tales of poor communication in healthcare and the adverse outcomes that follow.⁶⁴ While our medical indemnity providers encourage us to be open and transparent with our patients, the healthcare stories that gain the most traction in the media are those where the lack of open and transparent communication leads to the perception of a cover-up, real or otherwise.

The most recent example can be seen in the *ABC 4 Corners* story on Newmarch House,⁶⁵ the residential aged care facility in NSW where a large number of elderly people died from COVID-19. It seemed to us that the sources of greatest distress were the lack of communication about individual residents, the inability of family to visit, the clearly incorrect statements that residents would receive the same level of care that they would have had in hospital, and perhaps most importantly, a dearth of information about why patients were not being transported to hospital. The whole community has been left wondering if there was a policy that forbade admission to hospital and the reasons that underpinned that plan. In addition, the programme raised issues about the goals of advance care planning in the setting of Newmarch House as it

was described by the families of the residents.

As it turned out, so far COVID-19 has not overwhelmed our health system, and still the residents of the RACFs did not receive the level of care that they had been promised. While this outcome could not have been known in advance, irrespective of the outcome, an open and transparent communication strategy might have avoided much of the public anger, distress and mistrust that is evident in and from the *ABC 4 Corners* programme.

We believe that the risks of not creating and releasing guidelines for triage decision-making outweigh the risks of doing so. Unless we are to believe Australians are less capable of dealing with complex and difficult issues than the Germans and the Swiss, then one way to address the issue would be to start a community discussion about how we should make those choices. We may well find that it is not as difficult as some fear.

Finally, as physical distancing fatigue starts to set in, an open discussion about how to make exclusionary resource allocation decisions may well serve as a reminder why it is so important to avoid having to do so, and that we all have a role to play in protecting our community.

63. Kirkpatrick DD, and Mueller B. 2020.

64. Tian Y. How would you want the worst news of your life to be delivered? *The Guardian*, 15 October 2019, https://www.theguardian.com/commentisfree/2019/oct/15/how-would-you-want-the-worst-news-of-your-life-to-be-delivered?CMP=Share_iOSApp_Other

65. *No way in, No way out*, 4 Corners, ABC TV, 22 June 22 2020, <https://www.abc.net.au/news/2020-06-23/four-corners-newmarch-house-coronavirus-australia/12345726?nw=0>

Summary

This paper has been written to address the challenge of maintaining effective, high-quality palliative care for individual patients and their families over the course of the COVID-19 pandemic when governments must also make decisions that are in the interests of the community as a whole. We have already seen significant disruption to the delivery of palliative care to patients dying from causes other than COVID-19, and the pandemic may yet result in significant mortality from the virus itself.

It must be admitted from the outset that it is impossible to prepare for a significant global pandemic or a regional epidemic in a way that can guarantee to forestall mortality and prevent economic and social disruption. The random emergence of new mutations and the chance events by which novel organisms infect the human population mean that serious contagious diseases are unpredictable and may well be devastating. Human history has been shaped by such events and we know that they will continue to occur in some form or other from time to time.⁶⁶

However, since we know that epidemics and pandemics will happen, there are things that we should and can do to prepare both for the logistical healthcare responses to the diseases themselves and for the resource allocation, rationing and triage challenges that arise when the demand for treatment overwhelms supply. Part of that preparation is to design and prepare the systems for decision-making that respect both the wishes of individuals within the community and the expectations and needs of the community for open, transparent and ethically-sound decisions within the constraints of what can be very difficult times.

One of the most important tasks of every nation is to prepare for the possibility that its health system will not be able to meet the healthcare needs of its community to the level that they have come to expect. This requires asking and answering questions that confront our values and beliefs and challenge us to deal with issues that we would generally prefer to ignore. The process of deciding the priority a community places on its individual members is almost a taboo in an egalitarian community. But in the context of a severe pandemic when the binary choices of triage must be made, the design and implementation of guidelines for clinicians is not a task that can

simply be ignored. As we have seen in New York and Italy, circumstances can dictate that decisions be made irrespective of any organisational failure to prepare and sanction such decisions.

How does a democratic and egalitarian nation deal with such a challenge?

The first requirement is for leadership that trusts our community to engage in a process that openly and candidly addresses the gravity of potential challenges. In many ways this is actually a test of our leaders who must earn our trust that they will act honestly and transparently in all of our best short- and long-term interests and balance our needs as individuals and a community.

Secondly, preparation is best done in advance, when there is no pandemic, as a measured and consultative process with all stakeholders – the community of healthcare consumers, clinicians, healthcare system managers and politicians – working in partnership with ethicists and other relevant experts. The process must be fully transparent and open with the guidelines that are produced available to all who are interested. As described so candidly in the anonymous quote in the Preface, a large proportion of individuals in our community accept the need to make difficult decisions in the interests of the whole community. Clinicians must be given sufficient time to understand clear and prioritised criteria for which their government takes responsibility so they are not left with the moral distress of having to make decisions about which they are uncertain. It is not sufficient to issue vague suggestions as to how they might consider making choices.

Third, it is important to understand the scope of the problem, and not to imagine that the quantity of patients for whom such decisions be made is larger, or smaller, than it is. In all countries, the majority of people with COVID-19 have not required difficult resource allocation decisions because they have recovered from their infection – they have either been asymptomatic, have required only low-level symptomatic relief, or have required supportive care only. Others have chosen not to receive treatments because they do not wish to receive intensive therapy even though it might have become indicated. A further group may not be candidates for high-intensity treatment because they are already too ill and/or frail to tolerate such measures. Such patients require and should expect that their clinician will work closely with them to

66. McNeill WH, *Plagues and Peoples*, Random House, 1976

support them and their families to recognise which treatments would be futile and likely to cause more harm than good.

Fourth, for clinicians, dealing with patient choices and the inevitability that some patients will die means understanding and accepting that death is most often not a professional failure. An ICU nurse from Sweden was seen on the news saying,

“I am not too distressed when my one of my patients dies from coronavirus because I know that I have done my best.”

This nurse recognised that her role is to provide treatment to the best of her ability and that even with the best will in the world, she cannot control the outcome from disease.

Fifth, the likelihood of needing to make difficult binary choices of pandemic triage can also be reduced by slowing down the transmission of disease so that the numbers of seriously ill patients are spread over a longer period (*‘flattening the curve’*). This means that the community does have the power to influence its own fate and that it can obviate the necessity to make difficult pandemic triage decisions about the treatment of its individual members. However, when binary decisions are necessary, the guidelines for such decisions must be created by the community in partnership with governments and circulated early to the community at large and to the clinicians who must use them.

Sixth, we must continue to aspire to the highest standards of palliative care for all people who are dying, irrespective of the cause. At the same time, we will have to deal with the reality that COVID-19 and the necessary community response will constrain our ability to deliver what we know would provide the best outcomes for each individual. While symptom control and physical care remain important, the prolonged restrictions on normal social interaction are becoming an increasing source of significant distress, morbidity and even mortality.⁶⁷ This issue will need ongoing attention and vigilance for consequences that will linger after the pandemic has run its course.

Epidemics and pandemics are disastrous and chaotic. The complexity of their origins, of their spread, and of their consequences means that they will produce countless interconnected, unforeseen and unpredictable challenges. In our preparation for and response to a pandemic we cannot escape the humbling realisation that humans can never be in control of the rolling tumult of an event that reverberates across our biology, our ecosystems, our economy, our cultures and our nations, and

that we and our lives will never be the same as they were before the pandemic.

However, COVID-19 also provides us with the opportunity to reconsider how we function in a community. Those of us who work in healthcare, and particularly in palliative care, can take the opportunity to learn from our patients what is important for them in a finite life – their hopes, goals, preferences and wishes – and to reflect on what may have been for some a painfully close encounter with death.

As always, the interests of our community and each one of us in dealing with these issues will be best served by openness, transparency and honesty about all aspects of the challenge of dealing with COVID-19, including facing up to the risks and the uncertainties.

Finally, that we will not be able to simply wind the clock back to where we were in January 2020 is almost certainly not in all ways a bad thing.

67. Aronson L. For older people, despair, as well as COVID-19, is costing lives, *New York Times*, 8 June 2020, <https://www.nytimes.com/2020/06/08/opinion/coronavirus-elderly-suicide.html>

Appendix A

Compilation of examples of Australian and international government and institutional documents for triage

Many if not most jurisdictions across the developed world have created guidelines, policies, plans and strategies to deal with COVID-19. Given the variety and number, we have elected to reference a range of these documents.

New South Wales

Sydney University – Sydney Health Ethics: An Ethics Framework for Making Resource Allocation Decisions within Clinical Care: Responding to COVID-19 – <https://www.sydney.edu.au/news-opinion/news/2020/04/08/covid-19-ethics-framework-to-help-guide-decision-making.html>

Queensland

https://www.health.qld.gov.au/__data/assets/pdf_file/0025/955303/covid-19-ethical-framework.pdf
https://www.health.qld.gov.au/__data/assets/pdf_file/0026/955304/covid-19-icu-admission-guideline.pdf
https://www.health.qld.gov.au/__data/assets/pdf_file/0040/959953/sgmcm-guide-ethical-decision-making.pdf

Victoria

<https://www2.health.vic.gov.au/about/publications/ResearchAndReports/covid-19-pandemic-plan-for-vic>

St Vincent's Hospital (Melbourne)

SVHM COVID-19 RESPONSE

Patient Triage, Care Pathways, Resource Allocation and Multidisciplinary Support

ETHICAL PRINCIPLES, GUIDANCE AND PROTOCOLS

Western Health – Ethical Guideline for Clinical Care Decision Making during the COVID-19 Pandemic

Switzerland

Swiss Academy of Arts and Sciences

Intensive care medicine: triage in case of bottlenecks

<https://www.sams.ch/en/Ethics/Topics-A-to-Z/Intensive-care-medicine.html>

https://www.sams.ch/dam/jcr:c1f2b1d3-95d4-486a-8c59-e5668e74e97b/guidelines_v2_sams_triage_intensive_care_resource_scarcity_20200324.pdf

Borasio Gian Domenico, Gamondi Claudia Obrist Monika, Jox Ralf, COVID-19: decision making and palliative care, Swiss Med Wkly. 2020;150:w20233, Published 24 March 2020 doi:10.4414/smw.2020.20233

United Kingdom

National Institute for Health and Care Excellence

COVID-19 rapid guideline: critical care in adults

<https://www.nice.org.uk/guidance/ng159>

Palliative Care Australia incorporated ABN 85 363 187 904

P: 02 6232 0700

Unit 8, 113 Canberra Avenue

PO Box 124

E: pca@palliativecare.org.au

Griffith ACT 2603

Fyshwick ACT 2609

palliativecare.org.au



PalliativeCare
AUSTRALIA
