



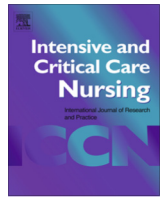
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## Editorial

# End-of-life decisions and care in the midst of a global coronavirus (COVID-19) pandemic



The unprecedented and unfolding global situation with Coronavirus (the virus SARS Cov-2, leading to the disease named COVID-19) (WHO, 2020) has forced health care providers across the world to consider end-of-life issues in a very rapidly changing scenario. During this pandemic, end-of-life decisions, in the face of finite critical care support such as staff, beds and equipment are necessary now more than ever. The reported global mortality is only an estimate, given not all countries, including the UK, are testing all those who are symptomatic. The spread and course of the disease has led to critical care services being overrun in many places across the world, and those who present to critical care with COVID-19 are the most severe cases and much more likely to die in critical care, up to 1 in 2 in the UK at present, compared with a usual mortality in critical care of 16% (ICNARC, 2020, 2019).

Doctors are being encouraged to have end-of-life conversations with people with chronic illness, ethics committees are hastily convened and in some parts of the world, health care providers have to face the prospects of no more critical care beds available. Some of these stretched services are unable to offer supportive critical care to all those in need.

Pandemic planning must encompass the wider issues of deciding who to treat and who should not be treated. Established ethical principles are challenged in pandemics. Terms such as reverse triage, where patients most likely to survive are prioritised and surge capacity, the ability to increase demand rapidly, are utilised (Pollaris and Sabbe, 2016). Canada led much of this work when H5N1 emerged (Christian et al., 2006), and again later when H1N1 was declared a pandemic in 2009. It is much harder to argue for individual autonomy, where individuals have a right to determine what happens to them in a resource-limited setting, as options are diminished. It is even harder for principles of autonomy to override the concept of utilitarianism, the greatest good for the greatest number, often cited in pandemics as an ethical framework (Conway Morris, 2015).

The COVID 19: Rapid Guidance for Critical Care (National Institute of Clinical Health and Excellence (NICE), 2020) published in response to the pandemic, places the focus on how and when to use frailty on admission to help patients, clinicians and families make rapid and timely admission decisions. Increased frailty is highly important and known to correspond to worsening patient outcome and increased mortality in critical care (Flaatten et al., 2017; Muscadere et al., 2017). This NICE admission guidance also encompasses end-of-life care decision-making and advanced care planning for those at greatest risk (NICE, 2020). Consequences of

admission have to be considered, and data already shows us that Coronavirus disproportionately affects those who are frail and, or with chronic health conditions (Yang et al., 2020). It is also highly likely that, despite this guidance, there will be limited critical care resources, as seen across the world in the face of this pandemic. Not everyone will be able to access the level of care they might need. The greater emphasis over the past decade on making timely and appropriate treatment escalation decisions that align with a person's wishes has, to some extent, paved the way for these conversations necessary in the current climate. Clinicians have to become confident in these conversations and about the implications of critical care for individuals. The long-term sequelae associated with ICU admission (post-intensive care syndrome [PICS]) includes physical weakness and/or psychosocial and cognitive morbidity, particularly when ventilated for a length of time (Desai et al., 2011; Kress and Hall, 2014). These PICS-related consequences can result in significant and persistent burden (Bagshaw et al., 2015; Iwashyna et al., 2010; Wade et al., 2015), and a much lower quality of life, even years later (Cuthbertson et al., 2010). However, in a pandemic scenario, it is rarely feasible to have meaningful conversations about a person's opinions and wishes about ICU admission because people are admitted acutely unwell. For patients with coronavirus in the UK there is rapid escalation to intubation, and sadly therefore little time for those discussions. By necessity, many family conversations are also taking place via telephone, with little opportunity for reading important non-verbal cues (Hall et al., 1995), thereby diminishing the quality of that end-of-life communication.

## End-of-life care

So, how do health professionals prepare for providing large scale end-of-life care in critical care in a pandemic? There has been a renewed focus on the disaster literature, following other infectious disease outbreak situations, and the H1N1 outbreak in 2009 in particular (Kain and Fowler, 2019), but end-of-life care planning within this rarely features. Coronavirus (COVID-19) has presented a new scenario given the large numbers dying worldwide from in critical care units, or makeshift units. Following the H1N1 outbreak and a surge in critical care demand, Downar et al. (2010) described the need for a palliative pandemic plan, with a view to providing palliative care outside the critical care unit. Downar et al. (2010, p 293) outlines four key aspects; *Stuff* (stockpiling equipment and palliative medication such as opioids, anti-psychotics for

delirium/nausea, antimuscarinic agents for secretions and syringe drivers, sub-cutaneous butterflies for medication administration); *Staff* (identifying staff with expertise, education, preparing protocols and guidelines for practice, ensuring grief/bereavement counsellors), *Space* (maximising existing palliative care beds/hospice facilities and identifying non-clinical areas appropriate for large numbers of people to die) and *Systems* (ensure advance care plans and care plans in place, triage for specialist palliative care, liaison across provider networks to access knowledge and facilitate direct access for clinicians needing consultation support).

The [Association of Palliative Medicine \(2020\)](#) have issued guidance this week to support palliative care clinicians providing palliative care in secondary care. Focusing on ward-based patient care, the guidance defers to critical care expertise around ventilatory withdrawal. These principles are already described in the [Faculty of Intensive Care Medicine \(FICM\) \(2019\)](#) end of life care in critical care guidance. However, in a pandemic situation, teams do not have the luxury of providing the best end-of-life care possible as advocated in the literature and guidance ([FICM, 2019](#); [Pattison and Campbell, 2016](#); [Pattison et al., 2013](#)). Adjustments have to be made, and expectations altered.

End-of-life care in these scenarios is pressured by rapid bed turnover, far exceeding usual bed pressures. COVID ventilation practices focus on limiting lung damage and minimising staff risk, and withdrawal of ventilation at end of life also has to minimise any risk to staff of aerosol exposure. Extubation, practiced at end of life in many countries but less commonly in the UK, is an aerosol generating procedure and may have to be reconsidered above turning off ventilators. Nurses and teams have to provide care in extreme situations, and may even be providing care in critical care which is outside their area of usual practice. Offering clear, accurate and consistent communication to patient and families at end of life in critical care in this situation is challenging, with senior critical care nurses bearing much of the brunt of managing these scenarios. Having access to equipment to provide supportive end of life care, such as syringe drivers outlined above, is also increasingly difficult as demand for supplies increases day on day while we approach the height of the pandemic. Creative care planning can help mitigate some of these challenges, and staggering end of life care and withdrawal across units to ensure nurses can be fully present with patients as they are dying. Initiatives such as critical care gardens ([Alexander and Tantam, 2020](#); [BBC](#)) are being expedited to ensure patients have humanising experiences in the midst of an unfolding disaster, and that end-of-life care provided is as good as it possibly can be. Ensuring a critical care nursing presence, an interpersonal process characterised by sensitivity, intimacy, vulnerability alongside empathy and holistic care, is key to this ([Finfgeld-Connett, 2008](#)). Critical care nurses are swiftly finding alternative ways to communicate with families, such as videoconferencing, as most families will not be present, given pandemic visiting restrictions in place across critical care units worldwide. Bad news may have to be broken this way. In these challenging times, person-centred critical care nursing and high quality, empathic communication at end of life becomes most important.

### Bereavement support

We know that 27,000 families are bereaved each year annually in the UK ([ICNARC, 2019](#)) and it is expected the rate will be raised in 2020 following Coronavirus. At the time of writing, 2926 patients had died in the UK, and 34192 (8.5% of all reported cases, although likely to be much lower as many more suspected cases remain untested) ([Johns Hopkins Coronavirus Resource Centre, 2020](#)) globally from Coronavirus, what is unparalleled is having to provide end-of-life care to so many unexpectedly. Families

bereaved in critical care experience worse outcomes, with a greater prevalence of PTSD (44%) and prolonged grief disorder (complicated grief) (52%) at six months than seen in the general population, which is around 5–10% ([Fujisawa et al., 2010](#); [Kentish-Barnes et al., 2015](#); [Lundorff et al., 2017](#)). Indeed, under these unusual pandemic circumstances we may well expect even higher figures of complicated grief.

Unexpected death is a marked feature of coronavirus-related death, and this feature of bereavement can lead to maladaptive coping and difficulty adjusting. These bereavement experiences are compounded by the fact that most families will not have been permitted to say their goodbyes in person. Nurses and doctors in critical care are having to inform families of bereavement by phone, or share last moments via teleconferencing and videoconferencing facilities, placing an enormous emotional and psychological burden on teams and individuals, as well as families. Usual meaning-making practices, so important for bereavement adjustment ([Park, 2010](#); [Milman et al., 2019](#)), such as fingerprinting, hair locks and patient diaries are harder, if not impossible altogether, to carry out. There is also a social legacy in disaster-related deaths, like in this pandemic. Collective grief, as seen in situations of high-profile deaths and disaster situations ([Kübler-Ross and Kessler, 2005](#)), is a recognised phenomenon, with shared mourning through bonding with strangers who have undergone a similar bereavement. This is really important for us to consider in terms of how we shape and provide bereavement support around COVID-related deaths. As [Kübler-Ross and Kessler \(2005\)](#) suggest, trauma in such circumstances invites us to learn about our strength, endurance and eventually reach hope.

Nurses' and other professional grief may also be compounded by being unable to care for families and patients as they might wish. Burnout, moral distress and moral injury has been identified as a significant issue in critical care professionals ([Colville et al., 2019](#); [Vincent et al., 2019](#)) and caring for each other, in order to be able to care for our patients and families is paramount. The weeks and months ahead are likely to prove even more challenging and when this pandemic abates, and normal critical care services resume, there must be time built into staffing rotas to regroup, come together as teams, recognise our own grief and have the opportunity to reflect on what has been achieved under extraordinary circumstances.

### Conflict of interest

NP was a contributing author to FICM (2019) guidance and contributed to the NICE guidance (NG 159) and FICM/NICE and NHSI/E shared guidance.

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