

End-of-life care during the COVID-19 pandemic—What makes the difference?

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1 | INTRODUCTION

The novel coronavirus SARS-CoV-2 (COVID-19) has rapidly led to a global pandemic, with a second and third wave following the first, presenting a hitherto unprecedented challenge for critical care staff. Intensive care units (ICUs) and corresponding health care professionals have been overwhelmed in almost all countries across the globe.¹ Current estimates indicate that ~10% of patients with COVID-19 will develop a severe disease, such as Acute Respiratory Distress Syndrome (ARDS), and require intensive care.² Although older adults represent a high-risk group with increased mortality—like other patients with comorbidities such as diabetes and cardiac disease³—young people without pre-existing illnesses are also severely affected.¹ During this pandemic, rapid and constantly evolving end-of-life decisions are needed. These decisions are influenced by factors such as judicious allocation of ICU beds due to scarce resources, acute life-threatening illnesses, unknown COVID-19 disease progression, and unexpressed end-of-life wishes. Due to severely restricted visitation policies, it is more difficult to involve relatives directly. This has a major impact on the relatives' end-of-life involvement and their consequent grieving process, resulting in mental health problems, such as depression, anxiety, complicated grief, and symptoms of post-

traumatic stress disorder.⁴ These symptoms have been described by the term “post-intensive care syndrome - family” (PICS-F).⁴ Moreover, the exponential progression of the pandemic, with a sudden and substantial increase in ICU health care professionals' workload, requires a focus on patient care. This may lead to relatives feeling neglected or as if they are only involved at a late and final stage of a patient's ICU life. In the face of these unprecedented challenges, there is no single correct approach to end-of-life care. Nevertheless, an in-depth examination of this subject is important for clinical practice. Therefore, the aim of this commentary is to (a) describe end-of-life care and decision-making structures and processes on ICUs, (b) explore their relevance in COVID-19, and (c) identify recommendations for practice during a pandemic.

2 | PATIENTS' AND RELATIVES' PREFERENCES—END-OF-LIFE WISHES

Many patients have died in ICUs worldwide during the COVID-19 pandemic. They were cared for by multidisciplinary health care professionals who did their best but who were often working at the limit of their technological, psychological, physical, and cognitive abilities.⁵ In pre-pandemic times, in adult critical care a decision on limiting treatment was often made beforehand for many patients in the ICU.⁶ As a result, dying sometimes became a relatively predictable process in ICUs, where distressing symptoms such as dyspnoea or anxiety were alleviated, relatives were involved, and support services could be consulted.^{7,8} Successful models for palliative care delivery and quality improvement in the ICU setting have been widely studied in the past.^{8,9} Based on recommendations from the Improving Palliative Care

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in the Intensive Care Unit (IPAL-ICU) Project, the key elements in the end-of-life care, and decision-making process are as follows: (a) integrating interdisciplinary, interprofessional teams, (b) timing of goals of care discussions, (c) patient's values, goals, and preferences, (d) communicating prognosis, (e) addressing prognostic limitations, (f) addressing family guilt, and (g) presenting goals of care options.^{9,10} In an adapted form, these elements can be very helpful during a pandemic.

1. Health care professionals in the ICU are routinely involved in supporting dying patients, as well as their relatives. The amount of such support required is substantial during a pandemic and does not appear to be comparable to any experience to date. Furthermore, end-of-life care and decision-making is always a complex process, involving various stakeholders—depending on the organization, for example, palliative care teams and consulting physicians. During this pandemic, decisions often have to be made under pressure due to the need for rapid bed turnover and are not always supported by an interdisciplinary team. Therefore, it is even more important that the skills, experience, roles, and functions of the health care professional are clear. If new functions arise or change, it is extremely important that these are communicated, both to ensure the safety of the patients and so that relatives know with whom they can communicate.
2. The dying process during COVID-19 is different for every individual, with many patients dying unexpectedly. While dying and death cannot be planned, the symptom management of dyspnoea, pain, and suffering, as well as patient- and family-centred care, are even more important because of the isolation and limited family contact with patients. Relatives are not mere visitors; they are the link to the patient, and thus to the planning and implementation of treatment decisions. The use of telemedicine can be helpful for the relatives and health care professionals, enabling them to discuss the various goals and procedures.¹¹ However, given the exceptional situation of the relatives, they may be overwhelmed by new technology and, therefore, not feel adequately supported. To address this, simple approaches and guidance on the use of electronic tools are needed.
3. During the COVID-19 pandemic, ICU health care professionals must care for patients before, during, and after death. Prior to COVID-19, health care professionals were often able to get to know patients and their relatives on an individual level, allowing them to form a better picture of who their patient is. Unable to spend such time during the pandemic forming individual relationships with their patients, ICU health care professionals may be given a photo of the patient and their relatives to help them understand who their patient is outside of the hospital setting. Creating these personal relationships between ICU staff and patients is important as emotional engagement is a crucial element of patient and family support. Another important factor with the potential to facilitate or challenge engagement with end-of-life care and decisions is the degree to which relatives accept dying and death. Moreover, relatives may experience feelings of guilt if they themselves have tested positive for COVID-19. A trusting relationship and interaction between the relatives and the health care professionals are crucial factors in how the situation is experienced and

tackled, and various corresponding strategies are described in the literature. For example, a checklist can prove helpful for relatives in preparing themselves for discussions with the health care professionals.¹² While only few patients in the ICU retain the ability to make decisions in the terminal phase of life, patients with COVID-19 are quickly intubated and there is limited time to discuss end-of-life wishes. Nevertheless, not dying alone—and dying without dyspnoea, pain, and suffering—is the wish of most patients and their relatives during the COVID-19 pandemic. Giving patients a little more time for family members to arrive to the ICU or enabling relatives to see the patient to say their goodbyes, by means of a video call or in suitable protective clothing, can make a big difference in helping with the grieving process. Even something as simple as having a moment alone with their dying patient can be extremely important for relatives,⁶ as is the perceived comfort and dignity of the patient. Cultural, spiritual, ritual, emotional, and religious needs are particularly important. For example, an impulse such as holding the patient's hand at a particular moment, or a ritual, such as the familiar voices of family members on a video call, may be of comfort to dying patients and would also be a personal task for relatives, offering some relief to ICU health care professionals.¹³

4. Clear, open, and consistent communication with both patients and relatives is an important part of end-of-life care. It is not just during a pandemic that talking about diagnoses, prognoses, and end-of-life care is difficult, but an adequate understanding of this information by the relatives is crucial for their coping and grieving processes. By helping relatives understand what is happening and why, decisions can be understood and reflected upon.

3 | DEATH OF NON-COVID PATIENTS

During the COVID-19 pandemic, non-COVID patients are still admitted to ICUs. It is important not to forget these patients and their relatives. Depending on the severity of their illness and condition, an end-of-life discussion is also needed for these patients and relatives. These relatives, who are already under considerable strain, now have the additional worry of their weakened family member contracting a COVID-19 infection while in the hospital. Furthermore, relatives of dying and deceased patients may experience a severe grief reaction with intense yearning or separation distress.¹⁴ Therefore, it is also important to consider providing help for these relatives in their grief, by facilitating follow-up visits to the ICU or through psychological or spiritual support. However, it is important to meet the individual needs of the relatives.¹⁵

4 | RECOMMENDATIONS FOR END-OF-LIFE CARE DURING PANDEMIC SITUATIONS

- Each ICU should utilize triage and end-of-life decisions based on national/international recommendations for providing emotional relief for patients.

- Provide needs-based, patient and family-centred end-of-life care whenever possible and make corresponding decisions in times of a pandemic.
- Utilize the skills, functions, and roles of all health care professionals in end-of-life care and decision-making.
- Provide family-centred approaches in caring for dying critically ill patients with and without COVID-19 such as writing a diary for family members.
- If possible, allow a relative/s access to the patient with corresponding full personal protective equipment or at least utilize video calls with the family during end-of-life care.
- Support relatives in the use of technical resources, for example, for making video calls or using other web-based applications.
- As health care professionals are not able to see emotions after a video call, they should ask about and address these reactions and emotions when they next contact the relatives.
- Include creative offers and rituals in the end-of-life care such as, for example, favourite music, telling stories, and privacy.
- Plan follow-up visits and offer consultations for relatives and psychological support.

5 | CONCLUSION

Providing end-of-life care for ICU patients during a pandemic is challenging. Individualizing end-of-life care is crucial even in a pandemic. Existing feasible concepts must be combined with pandemic-adapted concepts to allow patients to die gracefully in the ICU.

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