

Palliative Care Medicine: End-of-life care in the intensive care unit

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INTRODUCTION

Petr Strabanek, author of *THE DEATH OF HUMANE MEDICINE*, said:

“Medicine is not about conquering diseases and death, but about the alleviation of suffering, minimising harm, and smoothing the painful journey of man to the grave.”(2)

When death is inevitable, patient care must be tailored towards alleviating suffering. This can be facilitated through appropriate management of distressing symptoms including but not limited to pain. Application of investigations and/or interventions should have the ultimate aim of minimising harm and preserving the dignity and autonomy of the patient. This must involve careful consideration of the patient in the context of their physical, psychological and spiritual wellbeing through collaboration of the multidisciplinary team and involvement of the family in every aspect of decision-making(1, 3).

The intensivist caring for the dying patient needs to be familiar with the principles of palliative care, and must use these principals as a guide in their management of the patient from as soon as a decision is made that terminal care has begun. Comprehensive care of the critically ill patient in the intensive care unit (ICU) should include addressing the needs of both the patient and the family, focussing on improving the quality of end-of-life care provided(3).

This review aims to address the implementation of palliative care in the ICU, with a focus on some of the challenges faced by intensivists including the ethical considerations associated with withholding and/or withdrawal of therapy during end-of-life(EOL) care in the ICU.

WHAT IS PALLIATIVE CARE?

According to the World Health Organisation (WHO), Palliative Care is:

“an approach that improves the quality of life of patients and their families facing a myriad of problems associated with life-threatening illnesses through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other distressing symptoms – physical, psychological, and spiritual – experienced by adults and children living with life-limiting health problems. It promotes dignity, quality of life and adjustment to progressive illnesses, using best available evidence”(4)

Some of the principles of palliative care medicine include ensuring that patient care encompasses the following aspects:

- provision of pain relief;
- affirmation of life and regarding dying as a natural process:
- neither hastening nor postponing death
- integrating psychological and spiritual wellbeing to patient care
- allowing the patient to live as actively as possible, improving quality of life
- offering support to the family throughout this process and during bereavement, including bereavement counselling
- application of palliative care from the time of diagnosis in conjunction with other therapies, investigations and interventions to manage distressing symptoms.(5)

PALLIATIVE CARE IN THE ICU: EOL CARE

EOL decisions have become an integral part of ICU care. The ETHICUS study, a prospective observational study of European ICUs, showed that up to approximately 70% of patients who died in the ICU did so following a decision to withhold, limit or withdraw therapy on grounds of medical futility(6, 7). However, there is insufficient training of health care providers (HCPs), both physician and nurses, in end-of-life care decision making processes. HCP's need to have the same level of knowledge and competence in this area of ICU practice as is required for management of, for instance, the patient with respiratory failure. Therefore, the basic competences of palliative care should not only be included in the basic medical curriculum at undergraduate level, but continue throughout the HCP's career as part of continuing professional development.

Intensive care: “Intensively caring”

Montgomery et al. emphasize the concept of humanizing the ICU experience as high priority for intensivists. This involves consideration of the degree of benefit to be gained from the “suffering” inflicted upon the patient in attempts to prolong life. There needs to be a discussion of “pain vs gain”, with the multidisciplinary team, referring clinicians, and family(1).

Intensive care admission may unfortunately necessitate an inhumane degree of suffering which has been compared to commonly utilized components of psychological torture(1). Table outlines some of the features of routine intensive care and their similarity to forms of psychological torture(1). ICU admission is unavoidably associated with exposure to uncontrollable and unpredictable stressful stimuli due to the monitoring equipment, simple and/or complex investigation undertaken as part of clinical work-up, and invasive interventions inflicted on the critically ill patient in attempts to preserve life(1). The patient is seldom prepared for this “suffering” either due to an emergent need for critical care, or failure of the clinician to adequately inform the patient and family of the exact implications of an ICU admission. This is both a system failure, as well as failure of the HCP to inform the patient well in advance of an anticipated ICU admission in order to align patient and family expectations with the goals of medical therapy and the associated discomfort and suffering that this may entail. That being said, critical illness is often unanticipated and sudden, allowing little or no opportunity for rational conversations and considerations(1).

Feature of psychological torture	Comment
Fear of imminent death	Not unlikely in the critically ill.
Administration of mind-altering substances	Commonplace—whether benzodiazepines, opioids or other.
Humiliation	Bed-baths, enemas, incontinence, faecal or flatus tubes, or inadvertent exposure to strangers may all feel humiliating
Breaking sexual taboos	Exposure to strangers. Bladder catheterization.
Depriving of food and drink	Gastrointestinal tract tube feeding or i.v. feeding deprives patient of flavours. Poor regulation of fluid balance may cause thirst.
Perceived threats	Of death (above), indignity, pain, relapse or prolonged ICU stay.
Forced nudity/'feral treatment'	Bed-baths, cleaning after incontinence, medical examinations. Faecal soiling or urinary incontinence.
Exposure to heat or cold	Fever, limited bed coverings, impaired thermoregulation, surface warming or cooling.
Lack of natural light	Routine, as often few windows (so as to preserve privacy).
Constant or irregular light exposure	Lights having to be on at night for new admissions or for regular monitoring and treatment, for example.
Sleep deprivation	Referred to by the Romans as ' <i>tormentum vigilae/insomniae</i> '. Keep awake for long period, allow to sleep, then suddenly awoken. Not an unusual ICU pattern (noisy environment, lots of alarms).
Enforced confinement/isolation	To ICU, to bed, to one bed space, to a side room.
Sensory deprivation	ICU offers lack of choice over auditory input. Confined to one bed/one ICU with unchanging views. Limited range of (often unpleasant or unusual) smells. No food leads to no taste. Limited touch (especially if movement is restricted).
Social deprivation	On ICU, visitors may be restricted or unwilling/unable to come. Often one nurse attending.
Temporal disorientation	The denial of natural light, loss of clear day-night cycle, loss of routines or regular activities, such as meals/showers.
Sensory assault	Irregular alarms. New admissions/emergencies/regular treatment meaning noise and lights.
Induced desperation	Indefinite detention, perceptions of random 'punishment' (e.g. vascular access), forced feeding, suctioning of airway secretions, sense of abandonment or learned helplessness.
Awareness that others suffer	Hearing cries or shouts from another 'victims'. Awareness that others have died or are dying.
Debilitation and wounding	Whether bedsores, surgery or consequences of illness.
Demonstrable omnipotence of 'captor'	Staff know a great deal about patient, dictate 'daily living' and appear to have much control over their destiny.

Table 1.: Features of routine intensive care and their similarity to forms of psychological torture(1).

Therefore, it is imperative that, wherever possible, the wishes of the patient are established prior to their admission, preferably following an open conversation regarding the limitations of ICU care and some of the unpleasant experiences it may involve (1). Anaesthetists often have this unique opportunity to have this open conversation with colleagues, patients and family, ensuring that all parties are fully aware of the overall risk and benefit of major surgical interventions, and therefore allowing the patient to make an informed decision regarding the care they want to receive during the course of their illness, and if applicable, stating the preferred limits that should be applied(8).

Decision making: transition from cure to comfort

ICU care can aptly be described as a therapeutic trial. Once this therapeutic trial fails, led by the intensivist, the patient and family should consider a change in goals: from curative/restorative care to palliative/comfort care(8). The American College of Critical Care Medicine (ACCCM), in their recommendations for the end-of-life care in the ICU, highlighted the importance of a patient and family centered approach to end-of-life decision making(8). In this comprehensive approach, the clinician sees the patient beyond the presenting critical/terminal illness, but also as part of a social (family) structure, thus encouraging shared decision making. The family needs to be reassured that everything possible is being done to keep their loved one comfortable. Even when active treatment has been withheld or withdrawn, they need to be assured that their loved one isn't being abandoned(8).

Communication

Communication with families is an integral part of caring for critically ill patients(8). A family-centred approach that is based on the needs of the patient and family is crucial in ensuring their understanding of the patient's illness, prognosis and treatment options(8). Formal family conferences as well as bedside communication should involve supporting the family through the critical illness of their loved one and guiding them to hope for the best and plan for the worst, with ongoing direct communication of the patient's prognosis, and showing compassion by acknowledging the family's hopes for a good outcome while simultaneously preparing them for the possibility of the death of their loved one(8).

Good communication involves identifying and keeping regular meetings with the key members of the family, highlighting the major clinical problems initially and throughout the clinical course, and ensuring that communication is concise and consistent(9). In the initial family meeting, it is important to establish the existence of any advanced directives, outlining the diagnostic and treatment plan, and planning for subsequent meetings should these be required(9).

The ACCCM suggest the following framework for improving end-of-life communication in the ICU(8):

1. Communication skills training for ICU clinicians
2. ICU family conference to take place early in the ICU course
3. Interdisciplinary team ward rounds
4. Availability of palliative care and/or ethics consultation
5. Development of a supportive ICU culture for ethical practice and communication

Recommendations for conducting family conference include the following(8):

- Finding a suitable private location to engage with the family
- Spending more time listening to the family
- Using the VALUE mnemonic during such consultations
 - Value statements made by the family member
 - Acknowledging expressed emotions
 - Listening to family members
 - Understanding who the patient is as a person
 - Eliciting questions from the family members

Regrettably, evidence suggests that ICU communication with patients and family is inadequate, with studies showing that families are often dissatisfied with the quality of communication(6, 9). A study conducted in South African intensive care units revealed that the communication needs of the next of kin were not met(10). In the analysis, five major themes emerged that summarized the families' experience of EOL care in the ICU:

- (i) "most of the time we are in the darkness",
- (ii) "emotional support",
- (iii) "involvement",
- (iv) "family presence", and
- (v) "spiritual support"(10).

Negative experiences of the families far outweighed their positive experiences(10). A similar South African study looking at the needs of family members of patients admitted into a major trauma ICU found that the highest level of needs identified by the next of kin were in the areas of assurance and information(11). These findings bare similarity to other international studies in this field, thus highlighting the importance of improved communication with family members of patients receiving EOL care in the ICU(12).

Ethical dilemmas: Withdrawal of and/or withholding care

In an article entitled *The management of death in the ICU*, Dr RE Hodgson outlined some of the constraints prevalent in the South African state ICUs that hamper effective discussion of EOL issues with families(13). Being a developing country with the majority of the population in middle and lower socio-economic status, a predominantly poor education background, and given the vast cultural background of our citizens, language barriers often play a hindering role in effective communication between the intensivist and families. Cultural barriers may also hinder decision-making where the families may rely on a senior male family member to be solely responsible for making family decisions(13).

Furthermore, public sector intensivists are often constrained by limited bed capacity, requiring them to make decisions to maximise the utility of resources, and therefore the prolonged care of a dying patient may prevent provision of intensive care to another critically ill patient(13). Patients with a less likelihood of surviving are often refused intensive care, or conversely withdrawal of therapy may be warranted on the basis of futility. There is often limited opportunity to have extended discussions with the family due to the demand of ICU beds, thus potentially depriving families of the opportunity to come to terms with the inevitable death of their loved one, or the opportunity of being offered EOL care in an ICU environment.

When do we consider treatment withdrawal

Decisions to withdraw treatment should be individualized to the patient and their particular circumstances. Halevy et al. highlighted three broad categories that may be useful when considering the reasoning behind withdrawal of treatment(3):

- (i) **Imminent death:** this refers to patients who continue to deteriorate despite aggressive best therapy, and who are likely to die in the near future regardless of whether treatment is continued or stopped.
- (ii) **Qualitative reasons:** Withdrawal of treatment on the presumed basis of an overwhelmingly poor neurological outcome or functional outcome; cases where a patient would be in a continuing coma or severe neurological or functional disability, such as in the case of post-hypoxic brain injury.
- (iii) **Lethal conditions:** Patients with severe co-existing systemic disease, making prolonged survival after critical illness unlikely, such as in the case of metastatic malignancy(3).

The decision to limit ICU therapy in an individual patient already receiving intensive therapy depends on several factors including predicted mortality as estimated by primary physicians and the ICU team, but also the burden of treatment, quality of life, and expected functional status after ICU discharge(14). Furthermore, decisions on futility are made by the ICU team comprising of the intensivist and the ICU nurse as a central participant in this process. This is done by answering the question whether the efforts and resources being expended on each patient are saving the patient's life or prolonging his or her death(13). This is often not an easy decision to make and requires consensus between the treating team well as discussion with the patient's family to ensure that this decision is consistent with the values and objectives of that particular patient(9, 13). The family must be assured that every effort will be made to avoid discomfort(9).

Withholding vs withdrawal of care

Withholding life-sustaining treatments is defined as a decision not to start or increase a life-sustaining intervention, whereas **withdrawing** life-saving therapies is defined as a decision to actively stop a life-sustaining intervention being given(6). Most ethicists and professional bodies agree that withholding and withdrawing treatment are ethically and legally equivalent(6, 14).

Clinicians are psychologically more comfortable with withholding rather than withdrawing treatments (8). This may be related to the fact that withholding treatment is seen as a passive action whereas withdrawing treatment is viewed as an active process associated with a greater sense of moral responsibility(8, 15). There are also regional differences worldwide on how decision regarding withholding or withdrawing life sustaining treatment are made and to what extent families are involved(14).

There are a number of reasons for these considerable differences in practices in the various ICUs. These may include legal and regulatory issues and legal precedents within the country; the religious and/or cultural beliefs and practices of both the health care professionals and the patients and their families; the speciality of the attending physician; and the patient profile, which may include the medical condition itself as well as race/ethnicity and socioeconomic factors(8, 14).

Furthermore, some authors have suggested that withdrawing therapy may, in fact, be more ethically sound than withholding treatment. The rationale of this being that if withdrawal of therapy were not permitted, then many ICUs would be filled with patients who are hopelessly ill and are receiving ongoing treatment that is not likely to benefit them(6, 14). A common additional reason given for the soundness of withdrawal is that, if physicians are unable to withdraw therapies, there is a danger that they will not provide treatment, particularly in the acute situation, fearing that, once started, they will not be able to discontinue it. This approach may deny a patient the chance of receiving a potentially beneficial treatment. Consequently, patients who could have benefited may be denied potentially life-prolonging care. By allowing a trial of a therapy rather than withholding it, the patient will be given an opportunity of possibly benefiting from the treatment(14).

In addition, after the therapeutic trial, there will be less uncertainty and a better assessment of the patient's prognosis. If the physician's assessment is incorrect (which occurs not infrequently), then by withholding, no allowance is made for an error of judgment. Adopting this approach, the withdrawal of life-sustaining therapies is not considered the cause of the patient's death, as although patients may die sooner, the actions of physicians are considered "allowing the patient to die" from the underlying illness(14).

Practical aspects of withdrawing life sustaining treatment.

Prior to withholding and/or withdrawing life sustaining therapy, acceptance of medical futility needs to occur in order to facilitate transition from curative to comfort care. When confronted with a potentially futile situation we should ask ourselves whether quantitative, qualitative, physiological, imminent demise or overall futility applies and then direct care accordingly. The answers aren't always clear and clinicians must be comfortable dealing with uncertainties. The patient should be at the centre of all decisions and decision-making should always include the family(15).

Definitions and subtypes of futility(3, 16, 17)

- Physiological futility: treatment does not produce intended physiological effect, e.g. antibiotics are ineffective against viral infections
- Quantitative futility: treatment has <1% chance of succeeding, e.g. saving the life of an elderly patient with severe multiorgan failure
- Qualitative futility: Treatment that cannot achieve an acceptable quality of life, e.g. successful CPR resulting in a persistent vegetative state
- Immediate demise: starting treatment will not change the fact that the patient is imminently dying
- Lethal conditions: the patient has an underlying condition that will not be affected by the proposed treatment and that will lead to death within weeks or months

There are variable definitions of medical futility. Futility has a quantitative and qualitative component. Qualitative futility is the unacceptable likelihood of achieving an effect that the patient has the capacity to appreciate as beneficial. Quantitative futility refers to the unacceptably low likelihood that treatment will confer patient benefit and is primarily a medical decision. Qualitative benefit refers to the poor quality of the resulting patient benefit and this is a family/patient value-based decision. Medical futility itself is not a widely accepted term as it implies pointlessness or uselessness. It creates the impression that nothing further can be done and although this might be true when considering cure this is not the case for overall care(16, 17).

It is important to distinguish between withdrawal of care and withdrawal of life sustaining interventions. Withdrawal of care within an institution of care should never occur due to the fact that it remains part of our guiding ethical principles to sustain care even while we may withdraw life sustaining treatment. Care of the patient should continue fastidiously until death(8). The actual process of withdrawal of treatment is variable and there is no single universally accepted approach. Each individual ICU should develop standard protocols in order to guide this process of withdrawal of life sustaining treatment and withdrawal of mechanical ventilation(6, 14).

Preparation for treatment withdrawal :

- Ensure there is multidisciplinary consensus on the proposed treatment withdrawal process
- Evaluation of all ICU therapies in terms of whether they make contribution to patient comfort. If they do they should be continued. If not they can be stopped. For example antibiotics can be stopped whereas analgesia should be continued.
- Family should be fully informed about the process including the physiological and physical changes that may occur.
- The process should include
 - Access to appropriate spiritual care including appropriate cultural or religious rituals should be facilitated where possible.
 - Patient should be moved to a separate room and family should be allowed to stay with the patient through the process(6).

Withdrawal of mechanical ventilation

The approach to withdrawal of mechanical ventilation should be individualised as per individual ICU protocols. Terminal weaning involves gradually withdrawing mechanical ventilation. While immediate withdrawal of mechanical ventilation can be achieved by manual disconnection of the mechanical ventilator with or without transition to a t-piece or terminal extubation which entails removal of the airway without reducing ventilatory support . There is variable practice amongst clinicians with regards to withdrawal of mechanical ventilation, It is important to consider the advantages and disadvantages of each technique and to choose the technique that best suits the clinical circumstances(18).

END-OF-LIFE CARE DURING COVID-19 PANDEMIC

The Covid-19 pandemic has posed a significant strain on healthcare systems both in developed and developing populations(19, 20). This devastating pandemic has resulted in an unprecedented influx of severe ARDS patients dramatically exceeding ICU bed capacities in many countries(17). ICU preparedness is a key part of the response to the pandemic and clinicians must adapt and develop new ways to meet the needs of the critically ill patient(21). Most health authorities have suggested the implementation of specific strategies to save as many lives as possible(18). The Critical Care Society of Southern Africa (CCSSA) has published guidelines on ICU triage and rationing during this pandemic in order to streamline allocation of the scarce critical care resource (18). This involves using the clinical frailty score and SOFA score to prioritise the patients that are most in need and likely to benefit the most from the scarce resource. Unfortunately, the mortality rate remains significantly high.

Furthermore patients admitted to ICU generally have severe disease and a higher mortality risk. This poses a great challenge with regards to end of life care in these situations(20). Families with members admitted in ICU who are terminal are unable to be by their bedside during the end of life process due to COVID-19 pandemic restrictions. This restricts the involvement of the family in the final decisions related to EOL care of their loved one(20). This places the clinician a position that is in contradiction to the basic guiding ethical concepts of medical care.

“Of all the ways the coronavirus pandemic has undermined the conventions of normal life, perhaps none is as cruel as the separation of seriously ill patients and their loved ones, now mandated at hospitals around the world...” – a relative told the New York Times(20).

Clinicians need to be mindful and sensitive to this additional aspect in the end of life process, and attempt to keep the family updated telephonically at least on a daily basis.

CONCLUSION

Treatment withdrawal and/or withholding and end-of-life care in the ICU will always be a challenging area of ICU practice. Applying the palliative care principles needs to be part of every clinician's practice. Intensivists should strive to provide end-of-life care of the highest standard possible through research, continued education and quality improvement initiatives. Each unit should have clear protocols on the management of dying patients. Improved communication, support and involvement of the family needs to be part of our daily practice. Furthermore, even during these challenging times, we must remember that no matter how difficult the situation is, there is always something a clinician can do to make a difference to the patient and their family.

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