



## Review article

## Palliation, end-of-life care and burns; practical issues, spiritual care and care of the family – A narrative review II

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## ABSTRACT

Palliative care is the turn from cure as the priority of care to symptom relief and comfort care. Although very little is published in the burn literature on palliative care, guidelines can be gleaned from the general literature on palliative care, particularly for acute surgical and critical care patients. This second article discusses practical issues around palliative care for burn patients, such as pain and fluid management, withdrawal of ventilator support and wound care, as well as spiritual and family issues. This paper forms part two, of two narrative reviews on the topic of palliation, end-of-life care and burns. The first part considered concepts, decision-making and communication. It was published in volume 10, issue 2, June 2020, pages 95–98.

## Background

A fifteenth century folk saying describes the role of the physician as to 'sometimes cure, often relief, always comfort'. But with the great advances in curative care that were achieved in the twentieth century, relief and comfort have taken a backseat as illustrated by the regular appearance of studies demonstrating that in particular children with acute conditions are not given adequate pain relief [1,2]. In palliative care cure is deemed to be unlikely and the relief of suffering and patient comfort come to the fore again.

The Neuberger Commission [3] stressed that palliative care is not aimed at hastening death by depriving the patient of everything that sustains life, but to make the remaining time as comfortable and free of suffering as possible. It has in fact been pointed out that properly executed palliative care may prolong the patient's life [3]. Many of the problems associated with the Liverpool Care Pathway seem to be related to failure to make this distinction.

The aim of palliative care makes review of all current and proposed therapies imperative, with the aim of discontinuing those that are unnecessary, painful and/or uncomfortable. Where possible, the patient should be involved in these decisions. For instance, some dyspneic patients may prefer to have the ability to communicate with relatives, where others may want to be sedated. A study by Steinhauer [4] et al. suggested that patients valued being mentally aware higher than their physicians.

Hemington-Gorse et al. [5], identify the following concerns in palliative care for terminal burns patients:

- Relief of symptoms: pain, agitation, dyspnea, nausea and vomiting
- Wound and pressure care
- Psychological support
- Family support

## Respiratory management

Dyspnoea – the subjective experience of breathing discomfort - in the dying patient (Dyspnoea-Associated Respiratory Depression – DARD) is often multifactorial: In the terminal burn patient there may be inhalation injury and carbon monoxide poisoning as well as complications of treatment, such as fluid overload after over-resuscitation, a pneumothorax secondary to insertion of a central venous line, or a pneumonia. Anxiety and fear may cause a tachypnea which may be perceived as dyspnoea.

Pisani et al. [6] classify dyspnoea as air hunger (due to hyperinflation of the lung), increased work of breathing, chest tightness and tachycardia. Therapy should be individualized. The patient with air hunger or chest tightness would benefit from a bronchodilator, while a patient with tachypnea may find relief from oxygen.

Start with simple interventions, such as sitting the patient up, opening a window, keeping the room cool, or having a fan blow across

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the face. Supplemental oxygen will only be of benefit if the dyspnoea is secondary to hypoxemia. If this fails to improve the dyspnoea, it should be discontinued. Preliminary studies using high-flow nasal oxygen are promising, but further randomized trials are needed [6]. The mainstay of pharmacological treatment for terminal dyspnea is opioids. Morphine<sup>EDL</sup> is titrated to effect and is usually in the order of 0.2–0.5 mg/kg [6,7]. Respiratory depression is rare at this dose [8]. Fentanyl is contraindicated for DARD, as it can cause respiratory muscle rigidity. In anxious patients a benzodiazepine is often added, but these drugs have no effect on the dyspnoea as such. A recent Cochrane review concluded that benzodiazepines caused significantly more adverse effects than placebo, particularly drowsiness and delirium [9]. Sedatives should only be prescribed for dyspnoea that is not controlled by opioids. Terminal cough may be managed with opioids or aerosolized lignocaine (2 ml of 1% solution) [10]. There is no evidence to support the use of corticosteroids for terminal dyspnoea [6].

The decision to withdraw curative treatment may be made for a ventilated patient. Whether these patients should be extubated or not is controversial, and the pros and cons of each option have been discussed elsewhere, leading to a recommendation that the choice should be individualized [11]. If they are, excessive secretions leading to a ‘death rattle’ and postextubation stridor may occur, leaving the relatives with the impression of their loved one dying while ‘struggling for breath’ [8]. Although some studies seem to prefer terminal extubation, most of these were done in neurological patients without primary respiratory tract pathology [12–14]. Pham et al. [15] describe a protocol for withdrawing life support in ventilated burn patients in which they mention extubation as one of the options, alongside use of a T-piece, but do not express a preference. As burn patients are intubated for stridor or lower airway obstruction, it seems the more humane option to keep them intubated. If, however, terminal extubation is chosen, distressing symptoms, such as stridor and a death rattle, should be anticipated and treated before the tube is pulled. The patient is sedated, and all ventilator alarms are reduced to minimal settings. Inspired oxygen is reduced to 21% and pressure support and positive end-expiratory pressure (PEEP) to minimum settings. If this is tolerated without discomfort, the patient is disconnected from the ventilator and placed on a T-piece. Excessive secretions causing a death rattle can be avoided by stopping all IV fluids, furosemide in cases of pulmonary fluid overload, and treated with butylscopolamine (20 mg) or hyoscine hydrobromide<sup>EDL</sup> (0.4 mg).

## Pain relief

Pain relief for the terminal burn patient is not different from that for any other burn patient and includes the management of background and of procedural pain [16]. Background pain may be related to the depth of the burn wound, to infection and to dermatitis as a result of excessive exudation. Pain relief for the terminal cancer patient is guided by five principles, as laid out in the WHO pain ladder: pain management should be (1) individualized and situated to effect; (2) based on thorough knowledge of individual agents and their side effects; (3) by mouth; (4) by the clock; and (5) ‘by the ladder’, starting with mild analgesics, such as paracetamol<sup>EDL</sup>, building up to opioids (morphine<sup>EDL</sup>) if and when the need arises [7,17]. These principles may have to be modified in burn patients. Patients with major burns are usually managed with paracetamol plus a mild opioid, which represents step 2 on the WHO pain ladder. The WHO-ladder recommends Codeine<sup>EDL</sup> for step 2 pain management, this drug has recently become controversial [18] and the WHO has retracted this recommendation in children and new guidelines are being drawn up (<https://apps.who.int/iris/handle/10665/44540>). As burn patients often have poor circulation through

the subcutaneous tissues, muscles and gut, opioids may need to be titrated to effect via the intravenous route [5]. Intravenous paracetamol is an alternative to opioids for background pain, but is often prohibitively expensive. If no intravenous access is available, intranasal fentanyl<sup>EDL</sup> has been successfully used in palliative care, even in children below 6 months [19]. As adjuvant drugs, to decrease opioid-requirements, the following drugs may be used:

- antidepressants such as amitriptyline<sup>EDL</sup>.
- anticonvulsants such as gabapentin, carbamazepine<sup>EDL</sup> [20], valproic acid<sup>EDL</sup> or phenytoin<sup>EDL</sup> [7]. According to a series of Cochrane reviews [21], only gabapentin, but not carbamazepine nor valproic acid had sufficient evidence supporting a role in the treatment of neuropathic pain, a frequent component of burn pain. Gabapentin has been found to reduce opioid requirements in acute burns [22], and the African Palliative Care Association has recommended that it should be added to the EDL list for palliative care [7].
- alpha-agonists such as clonidine and dexmedetomidine are very expensive and not available in most African centers

Procedural pain may be managed with intravenous ketamine<sup>EDL</sup> or fentanyl<sup>EDL</sup>.

An essential element of terminal pain management is that the patient is regularly assessed for pain and that pain medication is titrated to effect. A number of scales are available to that effect, such as the Visual Analog Scale (VAS) for adults and older children [23], the Revised Faces Scale for younger children [23], and the Faces, Legs, Appearance, Crying and Comfortability (FLACC) scale for the non-verbal child [24]. Once an adequate level of analgesia is achieved, medication should be given regularly, not ‘PRN’ or ‘as required’, while assessing the patient every 4 h for breakthrough pain.

Although the risk of fatal respiratory depression is often feared in the context of terminal pain relief, there is evidence that appropriate pain relief does not shorten life but may actually prolong it [25–27]. Unrelieved pain is associated with a hypermetabolic and hyperdynamic response, both of which may exhaust the body’s reserves and hasten death and adequate pain relief may prevent this.

Pruritus can be disturbing and may be difficult to manage. Preventing dermatitis of the peri-wound skin by moisture-controlling dressings such as hydrocolloids, alginates or foam dressings, may be combined with pharmacological agents such as gabapentin or an antihistamine.

## Palliative sedation

Palliative sedation, using sedatives (midazolam<sup>EDL</sup>, chlorpromazine<sup>EDL</sup>, propofol<sup>EDL</sup>) is indicated for symptoms refractory to escalating treatment at the end of life, such as delirium, intractable pain or terminal dyspnoea [28]. It has replaced the term terminal sedation, because the latter implied that the goal was to shorten life [28]. Nevertheless, palliative sedation remains a controversial area in palliative medicine, because it is here that the boundaries with euthanasia are close and not always clear [29]. Ten Have and Welie [30] devoted an interesting study to this. The important distinction here is intent: the intent of palliative sedation is symptom relief, not sedation or death. The physician providing palliative sedation will therefore titrate towards symptom relief as an end point and maintain the required level of sedation when this end point is reached. When euthanasia is the end point, sedatives are increased until cardiopulmonary arrest is achieved. Although this seems rather straightforward, in clinical practice this proves far from being the case. Studies have shown that terminal sedation is more common when patients’ terminal phase is managed by general practitioners than by palliative care specialists [30]. One possible explanation for this is that the latter are better at symptom management and therefore less likely to conclude that the patient’s suffering is ‘intractable’, but it may also be the case that palliative care

<sup>1</sup> The suffix EDL indicates that the recommended drug is listed in the WHO Essential Drug List.

teams are better at communicating with the patient (who alone can determine whether the symptom is intolerable). To avoid this ‘mission creep’ of inappropriate palliative sedation by general physicians, it is advisable to include palliative care specialists when palliative sedation is considered. Another finding that is relevant for palliative care in LMICs is that in the United States for-profit hospices terminal sedation was more commonly offered than in public services: palliative sedation is cheaper and less time-consuming than adequate symptom management [31]. In LMIC settings this brings us back to the clinician's responsibilities in the context of limited resources that have been discussed in the previous article. Informed consent from the patient or the family should be sought before initiating palliative sedation [29].

In ventilated ICU patients, in whom therapy is withdrawn, sedation is continued until death, as abrupt stopping of, in particular, benzodiazepines can lead to seizures, tremors, confusion, anxiety, agitation and hallucinations [10]. Neuromuscular blocking agents should be stopped or reversed, as they hasten death, and may mask distressing symptoms.

### Fluid management and nutrition

Fluid management is a contentious issue in palliative care of the burn patient, and little is known about its effects. In palliative care of non-burn patients intravenous fluids have been associated with fluid overload because of failing renal function, with an increase in dyspnoea. It is probable that this may also occur in the terminal burn patient, particularly if initially no fluid resuscitation has been offered. Although not studied in terminal burn patients, in other settings intravenous fluids have not been shown to improve symptoms of dehydration [32].

The situation with regards to oral fluids is different. One of the issues pointed at by the Neuberger commission was that terminal patients were often given large doses of sedatives to suppress their thirst [3]. Terminal patients may be denied oral fluids for fear of aspiration. However, aspiration is extremely rare. The commission declared that denying a thirsty terminal patient fluids is to be considered medical negligence. A distinction that is sometimes quoted in this context is the difference between ‘natural’ and ‘unnatural’ life-sustaining interventions, with the latter including artificial ventilation, inotropic support, hemodialysis and nasogastric tube feeding. Court rulings, mainly in patients in a vegetative state, have stated that there is no obligation on a doctor to provide ‘unnatural’ interventions if he/she regards them futile. There can, however, be no argument to deny a starving patient food, or a thirsty patient a drink [3].

A dry mouth may be the result of medications such as anticholinergic drugs, opioids or antihistamines or of dehydration. Mouth care is imperative, and responsible drugs must be stopped [10].

### Delirium

Delirium is common in terminal ICU patients, and may be the result of inadequate pain management, central nervous system involvement, sepsis, substance intoxication or withdrawal, or a side-effect of medications [33]. It may be managed by adequate pain control, removal of unnecessary restraints and invasive devices that cause discomfort; or environmental changes such as placing the patient in a single room, establishing a day/night rhythm, and providing access for family members. If these are not successful sedation with neuroleptic agents such as haloperidol<sup>EDL</sup> may be offered. Benzodiazepines are contraindicated as they may cause paradoxical reactions [32].

### Wound management

There is no literature on the choice of dressings for the terminal burn patient. General principles of palliative care apply here as well. A number of articles have been published on the management of wounds

in the terminal patient, and these will be applied to the burn patient [33–37,39–40]. The aims of terminal wound care are to relieve suffering, and to avoid the family's last memories of the patient as soaking in foul smelling exudate. Wound bed preparation is no longer the overall aim of wound care, but control of infection and exudate as well as pain relief remain important concerns. The patient must be involved in the decision-making to ensure the right priorities are set. Terminal patients are at risk of pressure ulcers, through a combination of poor mobility, malnutrition and hypovolemia – a condition referred to as ‘skin failure’ [38]. Preventive measures, such as frequent turning, however, may be painful and priorities must be set according to the patient's wishes [34,37].

Procedural pain is related to the number of procedures a patient undergoes. As most burn patients will die within hours to days from the decision to withdraw therapy [38], a dressing that can be left on for 3–7 days will obviate dressing changes altogether. Odor is related to colonization with anaerobic bacteria, which maybe eradicate with prolonged-release antimicrobial dressings. Sprinkling the wound with crushed metronidazole may rid the patient of the smell. Activated charcoal will also absorb bad wound odors, as will honey. Terminal burn patients may lose large amounts of exudate and they should be dressed with dressings that can cope with this, such as a foam, hydro-fiber, or alginate dressing.

### Spiritual issues

Although most tend to identify spiritual issues with organized religion, they encompass more. Spirituality refers to the individual's search for meaning [41–47]. When confronted with the approaching end of their life, most people want to ensure that their life or their death has meaning [45]. As Hinshaw [44] remarks, ‘the challenge at the end of life is to restore and maintain the integrity of the dying person in the face of a clear and ever-present threat of disintegration.’ Patients find this meaning in a variety of ways, from the approval of their God to organ donation, from *karma* to the knowledge that they have provided for their families. In many HICs hospital chaplains are particularly trained and experienced to deal with such spiritual issues and some have even employed specific palliative care chaplains [45]. But this discipline is not available in many LMICs, and their place is taken by professionals (social workers, psychologists) and non-professionals (such as pastors with little or no training in counseling). An American study revealed that 77% of patients interviewed wanted their physicians to bring up spiritual issues, and 48% wanted their physicians to pray with them [47]. Steinhauser et al. [4] found ‘being at peace with God’ to be an important concern for dying patients, second only to freedom from pain. It is important not to be judgmental of established religious practices. Patients have the right to pastoral support of their choosing and if they have no access to such (for instance because they were injured far from their regular place of worship), a substitute from the religion and denomination of their choice. It has been shown that patients who had unmet spiritual concerns at the end of life had a significantly lower quality of life than those who had not [44,48].

The acronym SPIRIT has been developed to facilitate taking a ‘spiritual history’ [46]. The acronym stands for:

S = spiritual belief system: this refers to an organized belief system, such as Christianity, Hinduism or atheism

P = personal spirituality: what provides meaning to a person's life?

I = Integration: is and to what extent is the patient integrated in a religious community

R = Rituals: what rituals and restrictions are important to the patient, his or her family and religious community?

I = Implications: are there any implications of the patient's religious affiliations for medical care. It is important to view these implications not as ‘preferences’: they are necessities to the patient and his or her family

T = Terminal events planning: some religions place great value on

certain rituals surrounding the death of the patient (last rights in Roman Catholics, animal sacrifices in traditional religions) and all effort should be made to accommodate such.

### Care of the family

An often-forgotten element of palliative care is care of the family, including siblings and grandparents. What Mosenthal and Murphy [50] said about trauma deaths applies even more to burn deaths: they are ‘a tragic event, often afflicting young and previously healthy people’ and ‘rarely peaceful and dignified’. Alleviation of the family’s suffering through compassionate communication and support is an important goal of palliative care and how this is done may have long-lasting consequences [49,50].

Where-ever possible, relatives should be allowed free and frequent access to the dying patient and be given the opportunity to be together in a separate room or area when not with the patient. They should be directed towards sustenance (food and coffee). They should have access to counselors, both professional and spiritual. Dealing with dying children and their grieving siblings requires a specific set of skills and the involvement of pediatric-trained palliative care workers may be helpful [48].

After the death of the patient, families may need to be helped with the necessary formalities and supported in their grieving process (bereavement support). Mosenthal and Murphy [50] quote evidence that ‘family presence at resuscitation, death notification, breaking bad news, and the ability to see the loved one’s body are vital to the bereavement of family members’. It is helpful to offer the relatives the opportunity to discuss the events around the injury and death of their relative at a later stage, for instance after a week. This will allow them to raise questions, and express emotions related to the death of their relative. Better understanding their child’s illness and the reason for his or her death is known to be beneficial for families’ short- and long-term mental and physical well-being [51].

### Conclusion: implementation

Patients with massive burns that cannot be cured must be offered palliative care. These two articles have attempted to formulate guidelines for the care of these unfortunate patients. In the setting of an Emergency Center (EC) in Africa implementation of such guidelines may be problematic for a variety of reasons, These include lack of resources such as medications and dressings, or lack of time and space in an overcrowded EC. The development of full palliative services and a palliative care team [16] requires attention to each of the six building blocks of a health system (service delivery, health workforce, information systems, medical products, financing and leadership/governance) [52] but this will take patience and vision. Only for a number of countries in Africa, palliative services have been developed [53–56], while others do not even have morphine available for terminal pain [53]. However, this should not be a reason for African emergency physicians not to strive to apply the principles of palliative care to the dying burn patient, such as they were defined in the first article [38]: relief of distressing symptoms, and sensitive communication with the patient and the family. Emergency physicians are by nature geared towards resuscitative, life-saving interventions [56], but these may not be in the best interest of the patient with 90% burns and an inhalation injury. They may also lead to unnecessary utilization of scarce burn center resources including intensive care, and unrealistic expectations by the patient and his family [57]. The terminal burn patient represents an acute traumatic event affecting a patient who was well several hours before and is now dying, but is unique within this group of patients in that death may be delayed for several hours or even days. Proper terminal care for these patients is an ethical right [58].

### Authors’ contributions

Authors contributed as follow to the conception or design of the work; the acquisition, analysis, or interpretation of data for the work; and drafting the work or revising it critically for important intellectual content: DDH contributed 70% and JA and RA contributed 15% each. All authors approved the version to be published and agreed to be accountable for all aspects of the work.

### Declaration of competing interest

Authors contributed as follows: DDH contributed 70% and JA and RA contributed 15% each. All authors approved the version to be published and agreed to be accountable for all aspects of the work.

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