



Review article

Palliation, end-of-life care and burns; concepts, decision-making and communication – A narrative review

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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. Palliative care may be started because of futility, on request of the patient, or because of limited resources. The SPIKES acronym is a useful guide to avoid errors in communication with terminal patients and their relatives.

African relevance

- Mortality of burns presented to a burns unit in Africa is about 10%.
- Resources in Africa to manage burn patients are scarce and patients with massive burns may not be offered curative burn care.
- There are no guidelines for palliative care in burn patients.

Introduction

A 43-year-old woman had been brought in after she had set herself alight in a suicide attempt. Resuscitation ‘according to the Parklands formula’ had been instituted and the patient now had a ‘good urine output’. I saw an anxious-looking patient covered in gauze and crepe bandages that were smelly and soaking wet. When these were removed the patient was noted to have mostly deep burns covering about 82% TBSA. She had no signs suggesting inhalation injury.

In a Middle-Income Country (MIC), like the one in which we practice, patients like these cannot be salvaged. The extensive resources required are in limited supply or simply unavailable. The pressure on the few beds in the central burn units is immense as services in the district and regional hospitals are deteriorating as a result of the global economic crisis. Further, if this patient were to survive, rehabilitation and mental services specifically geared towards burns survivors and management of the psychological problems that precipitated this particularly painful suicide attempt are even in shorter supply.

End of Life Issues are seldom discussed in the burn literature [1], despite the fact that most burn units in Africa quote a mortality of

around 9% [2–6]. A search using the MedLine and Clinical Key search engines and using the terms ‘palliative care’ AND ‘burns’ yielded four descriptive articles describing practices around futility in a number of burns units around the world, none of which gave any information on how patients were managed there-after [7–10]. A short narrative review, quoting 8 references, only 3 of which were burns-specific, discussed end-of-life care in the burn/trauma unit from the nurse's point of view, but provided little practical detail [11]. Two articles were found that discussed palliative care in burn patients, one discussing terminal extubation in the ventilated burn patient [12], the other proposing a variation of the Liverpool Care Pathway for burn patients but providing little detail [13]. The Liverpool Care Pathway has – since the publication of this study – come under investigation [14], and the remainder of the literature exists in a number of letters arising from this discussion [15,16]. The existing literature therefore does not lend itself to a systematic or resource-tiered review and therefore the format of a narrative review was chosen.

Palliative Care is, however, discussed in other scenarios, including the surgical, critical care and trauma literature. Lessons learned and guidelines formulated in these publications can be applied to the terminal burn patient. The oncological literature on palliative care where a palliative approach is appropriate from the time of diagnosis, may be less applicable in the management of the burn patient, as the terminal burn patient usually dies within hours to a few days after the decision of futility has been made [10]. The following discussion is therefore mainly an application of the general principles of palliative care in the acute care setting to the burn patient. In this article we will

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address general principles of palliative care for the burn patient. In a second article we will discuss the practical issues.

What is palliative care

The term ‘palliative care’ was introduced by Balfour Mount in 1975 to encourage surgeons to consider the impact of treatments on the patient's quality of life rather than on the ‘30-day survival rate’ [17]. Palliative care (from the Latin *palliere*, to cloak or cover [18]), as initially defined, involves a ‘turn’ from cure to care, directed at the patient's quality of life and includes the relief of suffering, the avoidance of procedures without clear benefit to the patient, and the preparation of patients and their families to the approaching end of life. Recently, however, the definition of palliative care has been expanded to address serious health-related suffering throughout the course of an illness or condition. Palliative care, therefore, does not necessarily imply that curative efforts are abandoned [19], but rather involves the expansion of ‘traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family’ [20]. Prognostic uncertainty should therefore not be a reason to deprive a patient from the benefits of palliative care [21,22]. The WHO has in 2014 changed its definition of palliative care to ‘an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’ [23]. It has therefore been argued that palliative care is no different from standard care for any major burn patient. Principles of palliative care, such as realistic prognostication, attention to symptom relief and the avoidance of unnecessary painful procedures are important in the management of all such patients. Sometimes, however, the contradictory phenomenon is observed that the burn patient who is expected to survive is treated with all the benefits of symptom-relief and psychological support, while these are denied to the dying patient and his/her family.

Although in oncology palliative care is not the same as *end-of-life care* - the care of the dying patient - in the burns patient, the two usually coincide. Palliative care is a team-effort, involving nurses, social workers and psychologists, hospital chaplains, and pharmacists as well as medical officers. The term ‘interdisciplinary’ has been coined for this – stressing that the entire team must work towards common and cohesive goals [24]. Patients with major burns are usually managed by an interdisciplinary team with many of the above disciplines already mobilized. It is important that burn patients offered palliative care are not deprived of this team-approach.

Decision-making in commencing palliative care: futility, autonomy and distributive justice

The decision which patients with burns not to treat with curative intent, can be one of the most vexing for the burn surgeon and in a resource-limited setting will often have to be taken from a remote location with nothing but the assessment of a junior doctor, augmented by a series of cell-phone generated images. Transfer of all such patients to a tertiary unit is undesirable: it would overload the system, it would not necessarily benefit the patient, and it may impoverish the surviving family as the costs of repatriating the body to the community of origin are substantial. In a previous study Den Hollander [25] has highlighted the problems inherent to the concept of futility. These difficulties have sparked some to suggest replacing the term futility with *potentially inappropriate* [26]. Decisions not to treat a burn with curative intent may be based on the extent of the burn, the patient's expressed wishes, or limited resources:

Extent of the burn: Decisions not to treat a patient are often based on a severity score. Several scores have been developed to assess futility

[27], of which the Baux score and the Acute Burn Severity Index (ABSI) are the most commonly used, but they have a number of problems. Firstly, mortality prediction scores were developed as audit tools to assess the performance of burn units. They indicate at most a chance of survival but tell nothing about whether a particular patient will survive. Secondly, they were often developed and validated for populations in high income settings and may not apply to the situation in Low- and Middle-Income Countries (LMICs). Thirdly, only a few scores distinguish between partial and full thickness burns, or the severity of inhalation injury. Fourthly, none of the scores include typical LMIC-comorbidities, such as HIV/AIDS, tuberculosis and malnutrition, nor do they account for the influence of late referrals and the associated deficiencies in resuscitation typical of the LMIC setting [28,29]. And lastly, the use of burn mortality scores to guide futility decisions has not been explored in the literature. There is little to choose between the various scores, with different scores performing better in different populations [30–35]. In HICs death after a paediatric burn is a rare event, even after burns over 80% TBSA. Wolf et al., found a mortality rate of 33% in children with burns covering at least 80% TBSA, with over 70% of this full-thickness [34]. Risk factors for a fatal outcome were a very young age, limited donor sites, presence of inhalation injury, delays in resuscitation and sepsis or multi-organ failure. Rode et al. [36] suggested that, in the context of a Middle-Income Country the following should mitigate towards palliative care: a probability of survival under 10%, patients with destructive full-thickness facial and hand burns, irreversible hypoxic brain damage, and multi-organ failure.

The patient's wishes: The difficulties with relying on the patient's own decision, including the patient's wish not to be curatively treated, have been discussed in our previous study [25]. Patients with massive burns, although seemingly lucid during the resuscitation phase of burn injury, often have little recollection of what has been discussed with them at this time. On the other hand, any attempt must be made to find out what the patient's wishes are from either the patient or his or her family. For further elaboration on these points the reader is referred to den Hollander [25].

Scarce resources: Cancio et al. [37] argue that burn care in LMICs is characterized by limited resources, and is thus similar to that during disasters. In resource-rich settings young fit patients with massive burns and no comorbidities are usually given a trial of treatment even with near-total burns. Saving these patients, however, is extremely costly, as it involves long hospital stays, periods spent in critical care units, multiple procedures, and expensive resources including blood products, advanced dressings and antimicrobials. In addition, it requires experienced burn surgeons, anaesthesiologists, intensivists, nurses, rehabilitation specialists and a host of additional disciplines which are usually in short supply in LMICs. Even if these resources were available, overall funding may be limited, and decisions on how to spend the available money are still required and made by politicians. In South Africa where the burden of HIV, TB, trauma and violence are very high, the department of health has not prioritized burn care. This situation evokes many new ethical issues, such as whether it is ‘ethical’ to save the life of a patient with massive burns if ‘life’ means significant disfigurement or deformity in an environment where rehabilitation opportunities are scarce and the community unforgiving [38].

It should be acknowledged that some resources will always be limited in LMICs and decisions need to be made as to who will benefit most from them. However, when beds are insufficient, refusal rates may be too high. International guidelines for ICU triage have stated that in a democratic society doctors, ‘in addition to optimizing resource allocation ... must speak out and lead the drive to improve infrastructures’

[39]. This is best achieved through their professional organizations.

Poor prognosis and impending death are the most common reasons for withholding or withdrawing life-sustaining treatment for all age groups. In a study in neonates, poor long-term quality of life is a contributing consideration in over half, and the sole reason in a quarter. This is similar to decision-making in adult patients. However, in older children, physicians 'were more reluctant to use quality of life judgments' [40,41]. For the paediatric burns population there may be merit in this attitude. Sheridan [42], in a follow-up study of 60 patients who survived burns of over 70% TBSA in childhood, noted that, although 15% had continuing physical disabilities, the majority had a satisfying quality of life. They, however, remarked that comprehensive, multi-disciplinary burns after-care played an important role in recovery. This figure should be regarded against the suffering such an approach means for those that do not survive, particularly in low-resource settings. As Michael Gill asks, 'is the life of the one child that defies the odds worth the suffering of all the other children that succumb?' [41] A similar dilemma surrounds the argument that treating severely sick children now may benefit future patients with the same problems.

Whether treatment is considered curative or not, a palliative care approach must be adopted early to ensure the relief of suffering and holistic care [43].

Giving bad news

Communication with the patient is the *sine qua non* of palliative care. One of the major complaints against the Liverpool Care Pathway was that, once NHS trusts had started using the number of patients placed on the pathway as an indicator for hospital performance, families who had dropped an alert relative in hospital would return a day later to find them heavily sedated and dying. The Neuberger commission, who investigated complaints about the pathway, recommended that decisions to start palliative care should be made by experienced senior clinicians and only after discussion with the patient and his or her relatives [14]. In the LMIC setting, patients with massive burns often present to district general hospitals with only junior doctors on call. In this situation the decision to adopt a purely palliative approach must be made with a senior burn surgeon using a telemedicine link [44].

Discussion of end-of-life issues with patients or their families is difficult. They involve a patient that was healthy and full of life only hours previously. A number of reasons for this difficulty have been identified [45]. There may be unresolved issues in the doctor's own history, either personal (surrounding the death of a relative) or professional (guilt feelings about the death of a patient). Inappropriate expectations of one's role as a doctor may induce one to experience inability to save the patient as a personal failure [46]. Fear of litigation or of the displeasure of one's seniors cause doctors to deny the hopelessness of the situation. And lastly, discomfort with having to deal with the patient's or relatives' emotional reactions to bad news is an often-quoted reason for doctors' reluctance to discuss bad news (the 'MUM' effect) [47].

Even when end-of-life issues are discussed with patients and their relatives, health care workers are prone to making a number of errors that result in breaking down of communication [48,49]. In 'dumping' the doctor announces the bad news out of the blue, without 'firing warning shots', such as 'I'm afraid I have bad news for you'. This deprives the patient of the opportunity to mentally prepare for the bad news and creates a perception of the doctor as uncaring or rushing. When 'lecturing' the doctor provides all information about the disease and the proposed treatment in one go, denying the patient the opportunity to express emotions, digest the information and ask questions. It has been shown that in a bad news consultation, patients can digest no more than three bits of information at a time, and 'lecturing' will leave the patient overwhelmed. When 'blocking' the doctor ignores the patient's concerns or reacts to every attempt of the patient to express his

or her emotions by diverting the communication towards areas perceived as 'more safe'. The patient is left with the idea that his or her emotions do not matter or may be even abnormal. 'Collusion' occurs when both doctor and patient assume that sensitive issues will be brought up by the other party if deemed important. 'Premature assurance' is given when the doctor provides solutions before exploring the patient's concerns and expectations. When 'stalling', the doctor provides very detailed, technical information describing the events leading up to the bad news at length but delays the actual delivery or avoids explicitly stating the nature of the bad news altogether.

Yet poor communication of bad news can have important consequences, such as poor psychological adjustment [50]. In order to avoid the above errors in the bad news communication oncologists have developed the SPIKES acronym [47,48]:

S = setting. Avoid giving bad news in a busy emergency centre or hospital corridor. Create some measure of intimacy, even if it is only by closing the curtains round the bed. Sit down and switch off your cell phone or hand it to a colleague.

P = perception. Start the conversation by investigating what the patient/relative already knows and understands about the disease and its implications.

I = invitation. Find out how much the patient wants to know about the disease and its prognosis. Although most patients want to have a realistic picture about their injury, there are patients who do not, and information must not be forced onto them. This is also the time to fire the 'warning shots'. A study of Mosenthal et al. [19] in the trauma ICU highlighted the importance of communicating prognosis and realistic treatment goals with the patient's family on admission rather than when the situation becomes hopeless.

K = knowledge. Next, provide the information that the patient indicated he or she wants to know. Make sure to give the information in small bits, always checking that the patient has understood what you said and the implications thereof. Some call this the 'ask (perception), tell (give information), ask' (check understanding) principle [48].

E = emotions: allow patients to express emotions and reassure them that these are normal under the circumstances. It is vital that this is done with empathy, ensuring the patient feels heard and cared for. Patients often feel overwhelmed by their emotions (or by the lack of them) and their experiences may need to be 'normalized'. It is often not possible to proceed with the discussion until the emotion is dealt with.

S = summary and strategy. Finally, summarize the discussion and – if appropriate – plan for the future. What does the patient value? Is there something the patient still likes to do? What worries him or her? Who should be there? It is important that the patient is not left with a feeling of abandonment [51].

Patients expect their doctors to initiate discussions regarding end-of-life issues and their preferences regarding the kind of care they want to receive, but the experience is that many doctors leave such discussions until the last moment, when death is hours or days away [52]. Palliative care is a team effort, and the burden of communication – like the burden of palliative care – need not rest on the shoulders of an inexperienced community service officer, but that is a team of people that can assist.

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

The authors declare no conflicts of interest.

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