

CRITICAL CARE AT THE END OF LIFE

Balancing technology with compassion and agreeing when to stop

Montgomery, H. MB BS BSc FRCP MD FFICM¹

Grocott, M. MB BS BSc MD FRCA FRCP FFICM²

Mythen, M. MB BS MD FRCA FFICM FCAI (Hon)³

¹Professor of Intensive Care Medicine, University College London

²Professor of Anaesthesia and Critical Care Medicine, Critical Care University of Southampton, United Kingdom

³Professor of Anaesthesia and Critical Care, University College London

Address for Correspondence (to be addressed to all authors)

C/O MONTY MYTHEN

Inst Sport, Exercise and Health

1st floor, 170 Tottenham Court Road, London W1T 7HA, UK

Email: m.mythen@ucl.ac.uk

Mob: 07710 422073

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Summary (165 words)

Modern intensive care saves the lives of many. However, the substantial related financial costs are, for many, married to substantial costs in terms of suffering. In the most sick, the experience of intensive care is commonly associated with the development of profound physical debility which may last years after discharge. Likewise, the negative psychological impact commonly experienced by such patients during their care is now widely recognised- as is the persistence of psychological morbidity. Such issues become increasingly important as the population of the frail elderly increases, and the health and social care services face budgetary restriction. Efforts must be made to humanise intensive care as much as possible. Meanwhile, an open conversation must be held between those within the medical professions, and between such health care workers and the public in general, regarding the balancing of negative impacts of intensive care with the positive. Such conversations should extend to individual patients and their families when considering what care is genuinely in their best interests.

Introduction

There is no doubt that the availability of modern Intensive Care has been of great service to many. Many who would once have faced certain death through sudden and unanticipated illness are alive, who would otherwise not be. Likewise, survival from major surgical procedures is enhanced- making such procedures more widely available than ever before. Partly as a result of such success, and with enhanced public and professional demand, the number of intensive care beds and staff is increasing. However, intensive care can be associated with substantial suffering and is, for some, futile. Survivors (particularly of unplanned admission) may face reduced life expectancy, and many suffer a sustained and significant reduction in functional capacity and mental health. In determining which patients to treat, and the nature and extent of that treatment (limitation or withdrawal), intensive care clinicians must balance technological capability with the wishes and expectations of patients (and, given that these are often hard to determine, those of views of family, friends, carers, and staff). This is all the more important when the provision of intensive (and expensive) intervention draws from a finite funding pool that might otherwise be used elsewhere. The challenge, then, relates not only to deciding what to do, but what *not* to do. It is time to extend this conversation beyond the intensive care community and to have it openly, such that individuals, healthcare professionals and society more broadly, might better decide what sort of care they consider to be rational, affordable and compassionate.

Intensive Care Has Expanded

Sixty-three years ago, polio patients were ventilated (by hand) for the first time. Continuous haemofiltration was first used just over 30 years ago. Now, mechanical (as well as pharmacological) organ support is routinely available to UK adults, as is the application of sophisticated invasive and non-invasive physiological monitoring. Such technological innovation, together with demographic change, the evolutions of complex treatments in other disciplines, and changes in public expectation, have driven an increase in use of Intensive Care Unit (ICU) services. In response, at the turn of the century, England's Department of Health increased ICU funding. In 1999, there were 2240 ICU beds in England. There are now nearly 4000 with nearly a quarter of a million patients being treated each year.¹ Across Europe there are now more than 70,000 beds (11.5 per 100,000 population).²

Intensive Care Comes at a Cost

Such care is expensive. The annual expenditure on critical care in England increased in real terms from £700m (1999-2000) to £1bn (2005-6),³ and appears unlikely to decline in the near future. Such rising

expenditure comes at a time when the NHS faces an estimated £30bn 5-year funding shortfall, and when NHS England call for the nature of healthcare to be reconsidered.⁴

Sadly, intensive care may also entail substantial suffering for patients. The analogy with torture is illustrative. Torture is an “aggravated form of cruel, inhuman or degrading treatment” which involves the infliction of ‘severe pain or suffering, whether physical or mental’, and specific features of psychological torture are well documented.⁵ Whilst intensive care does not involve the ‘wanton’ (deliberate and unprovoked) ‘infliction of physical or mental suffering’ (the World Medical Association’s 1975 Tokyo Declaration definition of torture), modern practice results in many ICU patients being exposed to multiple factors that would be defined as torture in other contexts, even if only as a ‘consequence of good intent’.⁶ ⁷ (Table 1). It is possible to mitigate many of these elements: choice of analgesia (regional/ opioid sparing) and sedation can be changed and drug doses reduced where possible; efforts to maintain a circadian rhythm of activity, light and sound (with efforts to minimise intrusive light and noise exposure), and to reduce fear and sense of threat and to improve social contact, can be made. The environment can be ‘humanised’.

The consequences of exposure to true psychological torture are protean. Acutely, a severe limitation in social and environmental stimulation can cause agitated confusion, or even florid delirium with paranoia or hallucinations. Subjects may become stuporose, with sudden and intense arousal on stimulation. Difficulty in thinking and concentration, agitation, irritability, and difficulty tolerating external (especially noxious) stimuli are commonplace. Impaired memory and concentration; anxiety and depression; insomnia, sleep disturbance, nightmares and other intrusive phenomena; emotional numbing and social withdrawal; sexual disturbances; apathy, lack of energy, and helplessness can all result. Flashbacks, mistrust, avoidance behaviours, hyper-arousal (irritability, sleep difficulties, hyper-vigilance, constant anxiety, and depersonalization (feeling detached from one’s body) are also reported.⁸ Such features are also well recognised to occur in ICU patients— both acutely and for prolonged periods during “recovery” (see below). For example, florid ‘ICU Delirium’ (a disturbance of consciousness and cognition that develops over a short period of time (hours to days) and fluctuates over time) is identified in upwards of 20% of patients cared for in ICUs, and up to 80% of those that are most sick.⁹ Whilst in part related to the illness itself, such impacts may also be the unsought consequence of well-intentioned care.

Outcomes After Intensive Care

Such fiscal and psychological costs may be considered worthwhile if death is prevented, and if a long and happy life (or, at least one of acceptable duration and quality) follows. But for many, this is not the case. In England, more than 1 in 10 of those admitted to hospital as an emergency is readmitted within 28 days of discharge from hospital.¹⁰ In the USA, up to 20% of Medicare patients are readmitted within 30 days of hospital discharge. A cycle of readmissions from home to hospital, and thence from ward to ICU, may result, many such ‘hospital-dependent patients’ being ‘old, often with multiple chronic conditions’ and with ‘minimal physiological reserve to compensate for acute stress or injury’.¹¹ Such a pathway is associated with progressive functional decline¹¹ until death ensues - a death which is increasingly likely to be a ‘high-technology’ one. One fifth of patients admitted to ICU in England, Wales and Northern Ireland, and many more where such admission is as a medical emergency.¹² Many do so on the ICU itself. By 2004, one in five Americans who died already did so on, or shortly after admission to, an ICU¹³ and this rate is increasing over time. But alarmingly, many ICU survivors face profound physical debility: aggressive and rapid muscle wasting is common in the critically ill, with some patients losing nearly 30% of their lower limb muscle in the first week.¹⁴ Such impacts contribute to the significant limitations in functional capacity which affect 70% of critical illness survivors- debility which can last 8 years or more.¹⁵ Overall, 30% are still dependent on the support of family and professional carers at 12 months.¹⁶ Even a year after UK ICU discharge, income was reduced for the families of 28% and the number of patients for whom employment was the sole source of income had halved¹⁷. One-third of patients of working age will never

work again.¹⁶ One in five needed care assistance, generally from family members- whose employment was itself impacted in more than half. Three quarters suffered moderate or severe pain.¹⁷

It is not only physical function which is degraded after critical care. A 'dementia-like' cognitive impairment may affect the majority after ICU discharge, and may be longstanding (45% are affected 2 years later)¹⁸ or even permanent. Depression is also a common consequence of ICU admission, affecting up to 61% in the first 5 years.¹⁹ In the UK, 44% remained significantly anxious or depressed a year after ICU discharge.¹⁷ More than 25% suffer post-traumatic stress disorder after ICU care.²⁰

These impacts can affect the 'previously well'. But ICUs increasingly admit those with multiple chronic comorbidities, pre-existing poor functional capacity and limited life expectancy. It has thus been argued that disproportionate or inappropriate Intensive Therapy is commonly practiced in developed nations,²¹ with serious negative impacts on patients, their carers (professional or otherwise) and on society.¹⁷ Many might feel that it is time to change.

Intensive Care vs. Intensive Therapy

Intensive *Care* Units have drifted towards becoming Intensive *Therapy* Units. For many, this has been a good thing: survival after major surgery, for example, can be enhanced by such care. In other cases, however compassion may be compressed by a demand for technical interventions, and the increasing ability to deliver them (so called "provider bias" or "supply sensitive care"). Practice of such 'disproportionate care' may in some cases verge on the unethical when practiced by those whose professional ethic guides to 'first do no harm' to the individual patient, or to others considering broader societal issues when state healthcare budgets are constrained²¹. What, then, to do?

Humanising the ICU experience should be the highest priority for intensive care professionals. The suffering we inflict must be minimised. Diurnal rhythm and sleep, and pleasant site and smell, should be maximised. Pain, the administration of disorientating drugs, and noise, should be minimised. But clinicians should be careful about inferring the balance of 'pain versus gain': in some circumstance patients might prefer deep sedation and poorer outcome to the reverse situation, were they able to express an informed opinion. Research efforts can be made to identify and treat the causes of skeletal muscle wasting. Enhanced communication strategies can be employed. Access to experienced clinical psychologists may be of value.

Secondly, we intensivists must open a conversation amongst ourselves and then with medical professionals outside the intensive care unit, such that they understand the limitations of such care, and the suffering which it may entail. No longer should we receive referrals which state that a family or patient 'want everything', when neither clinician, relative or patient really grasps what 'everything' really means and where it might lead, and when expectations are often unrealistic. Few may be aware of the likelihood of ensuing pain and suffering followed by physical and mental disability, in the context of a pre-morbid state which is rarely improved upon.

Thirdly, it is a feature of critical illness that it is often unanticipated and sudden, giving no opportunity for rational conversation and consideration. If futile intervention or unwanted suffering are to be avoided, patients must be made fully aware of the limitations of intensive care, such that they can make decisions 'in advance'. It is often too late when the patient is hospitalised, let alone when a sudden decline has begun: the full benefits of collaborative ('shared') decision making are only realised when the conversation begins early. They can begin long before, when the citizen is still at home, and before crisis has struck.²² Whatever, options and choices should be balanced with humanity and compassion.

Finally, we all need to be braver about holding 'difficult' conversations such as these with colleagues and patients. As clinicians, we should think carefully about offering therapies to others that we might under similar circumstances not wish to receive ourselves. Such conversations are relevant to theatre-based anaesthetists, who have a valuable role to play in holding early discussions about the overall risks and benefits of major surgical interventions. Where risks of death are quoted, relatives are sometimes surprised that this can include death after prolonged or repeated ICU admission, rather than in the immediate perioperative period or 'on the table'. By far the majority of doctors would not like their lives prolonged if 'the likely risks and burdens of treatment would outweigh the expected benefits' or if suffering 'an incurable and irreversible condition' that would result in death.²³ Doctors are also more likely to seek treatment which involves less suffering but a lower chance of surviving, than they are to recommend such pathways to patients.²⁴ When invited through collaborative decision-making, patients and carers many patients also appear to decline intervention when aware of the full spectrum of consequences.²⁵ But it is often emotionally easier in the short term to 'just accept' escalation to intensive care, even when the outcome may be poor, and suffering great. We should be bolder in our compassion for others.

This discussion takes place against a background of resource limitation. Healthcare funding is not limitless and continuous growth never sustainable. Increasingly, any expenditure in one sector will restrict funding available to another. The equitable, appropriate and compassionate allocation of scarce healthcare resources is arguably the greatest challenge facing healthcare workers of the future. Delivering it will not be easy. Balancing the possible with the desirable and managing the expectations of patients, carers and colleagues, may prove harder than simply extending the limits of the possible. But efforts to balance the application of technology with communication, care and compassion is in the best interests of us all.

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 catheterisation.
Depriving of food and drink	GI tract tube feeding or intravenous 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 of 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 'tormentum vigilae/insomniae'. Keep awake for long period, allow to sleep, then suddenly awaken. 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 -> no taste. Limited touch (especially if movement 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 like 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: Patients in Intensive Care Units are routinely exposed to the commonly utilised components of psychological torture. Of especial note, uncontrollable and unpredictable stimuli are much more stressful than are predictable ones. In ICUs, this may relate to audible alarms (at the bedside or nearby), or the sudden need for investigations or for interventions (a new central venous or arterial catheter, or haemofiltration, for instance).

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All authors contributed to drafting, editing and revising of this manuscript. All give approval to this manuscript's publication, and agree to be accountable for it.

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