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# Treating the Whole Human in Intensive Care – Patient-Centred Outcomes in Sepsis, Surgery and Trauma

Intensive care impacts more than the patient, with ripple effects for families, employers and wider societies. Patient-centred outcomes reiterate the need for clinical therapies targeting the biological circuitry of the big-hitting syndromes like ARDS, sepsis, delirium, renal failure and recognising they persist beyond the veil of discharge.

The human experience is a rich panoply of highs and lows, an emotional sinusoidal journey that attracted even the meddling of gods in the ancient world. There is no human that will not die and no family that will not experience loss. Yet in the developed world, these experiences and conversations have become hurried clinical conversations corralled within breeze block walls and concrete struts, veiled from view until we are biologically, scientifically convinced this is an irreversible descent.

As physicians to the sickest patients, it is our role to guide them and their families/loved ones on this path and help them expect and adapt to new realities. The losses are not just physical; a day in an intensive care follow-up clinic – still not the standard – will leave your mouth dry and your heart thudding. Their sleep, dreams, memories, jobs, and relationships are shattered. No man is an island, and the stormy waves of survival beat against their spouses, friends and children, too.

What we may not realise is that we bear some responsibility for what we do to patients in our care, even as it is vital for their organ perfusion and intracellular chemistry. What was poignant in our experience of follow-up clinic was the delusion, fully realised, that an addled brain would devise to make sense of the wider world. Overwhelmingly, rolling and transferring

patients made them feel they were being kidnapped, smuggled, abducted and trafficked. Drapes for central lines made them feel smothered. Needles and procedures in the neck made them feel they were being decapitated or murdered. Even without these delusions, orientated patients had to fear for their lives, day in, day out, sometimes for weeks, as did their families. These are the precise series of events that leave many with post-traumatic stress. Many still cannot work, care for young children, or have ongoing sexual-emotional travails with their spouse – sexual dysfunction alone is significant in men after intensive care.

Morally, we are not fulfilling all that a human life is if they cannot re-integrate into society, even if we can wean them off a ventilator or treat their VAP (ventilator-associated pneumonia).

Here we will explore what is known about 12-month outcomes in intensive care, how we should design studies, and what interventions have proved successful in fully realising the human and financial cost-benefit of critical care.

## Outcomes in Sepsis

One 2019 study in North Carolina found that. When it comes to COVID-19, 12-year outcomes include 40% were still experiencing symptoms (Morgan 2021). COVID-19

has highlighted the prevalence of the post-intensive care syndrome, and more interest and data have been delivered as a result.

Up to five years of outcome data were summarised nicely by A Morgan (2021). Tracheal stenosis can occur in as many as 30% of those with tracheostomy, pulmonary function tests are still reduced 12 months after ARDS in 2/3 of patients, 20% of muscle mass can be lost in the first week alone of ICU, and genitive outcomes 12 months post admission are stark – 1/3 report cognitive function as severe as moderate traumatic brain injury and ¼ those akin to mild Alzheimer's (Morgan 2021).

Socioeconomic data following ICU is scarce, but a striking U.K. audit (Griffiths et al. 2013) demonstrated that 12 months after discharge (after being ventilated for 48+ hours), 1/5 are not independent on ADL, more than 1/5<sup>th</sup> of those requiring 50 + hours a week, 80% of which was provided by relatives – with a huge ripple of impact beyond the patient admitted. Those needing such care had to obliterate savings, sell their homes/remortgage, and use charities. In the 40% of patients previously employed before admission, 1/3 were no longer working or had reduced hours, with 1/3 reduction in family income and increased state benefit requirements.

## Outcomes in Surgical Emergencies

An audit of emergency laparotomies in a hospital in Northern England found a 12-month readmission rate of 40% and 12-month mortality of 40% - 2/3 had been previously independent (Vilches-Moraga et al. 2020).

ICUdelirium.org is a website dedicated to exploring the 'survivorship' of intensive care. Patients may share their experiences. For example, *"I had septic shock four years ago from urosepsis, and I'm in my 50s. I am writing because I have never felt like myself again. I can't think clearly; my memory has suffered, and I am fatigued like never before. Before sepsis, I was active, hiking, biking, rock climbing, and running, and now I am sedentary with no sex drive (also new) and a great marriage plus 40 lbs. It's been two years, and I'm still trying to sort out what was real and what wasn't. I still think about it several times a week and continue to ask questions of my family. I have a compelling need to know what happened to me. The final diagnosis was ARDS and Encephalopathy, however; they never determined the cause"*.

## Outcomes in Trauma

There exists heterogeneity not only in the physiology - both in health and disease - of the major trauma patients in whom we expect to exact clinical benefit but also in their emotional, cognitive and aspirational priorities once they leave the hospital. Practically, the data capture of these subtleties may be too complex to distil into binary figures or simple linear gradation systems. If so, we must be meticulously cognisant of this before ascribing unmodulated success to the discharge of a patient with a modified Rankin score of 1 whose intrusive thoughts, hypervigilance and short-term memory loss slip through the coarse net of performance status indices.

A 2012 consensus meeting acknowledged the need for more sensitive, multiparametric scoring systems in the endeavour to improve long-term patient outcomes from major trauma, a sentiment that has been echoed for both adult and paediatric

patients (Ardolino et al. 2012; Collins et al. 2022). Scoring systems referenced include the Nottingham Health Profile, the EQ-5D, the SF 36 HF, and the more recently validated and often favoured Trauma Outcome Profile (Kaske et al. 2014; Martino et al. 2020). Standardising long-term outcome metrics might help to both harmonise the lexicon in future research and serve as an intrinsic reminder of their importance.

**■ ■ morally, we are not fulfilling all that human life is if they cannot re-integrate into society, even if we can wean them off a ventilator or treat their VAP ■ ■**

Major trauma disproportionately affects younger populations compared to other critical pathology, and, therefore harbours the potential to disrupt more quality of life-years than other disease processes. While we are aware of the consequences, the solutions are either less obvious or difficult to achieve universally. Systematic reviews demonstrate that major trauma patients as a subgroup of ICU hospitalisations experience a greater magnitude of quality of life reduction than their counterparts, and higher aggregate ISS and severe head trauma are predictive of even more severe outcomes. Younger patients and those with higher ISS and SOFA scores were also more susceptible to intrusive thoughts and delusional memories during their ICU stays and, in turn, tended to exhibit higher incidences of anxiety and depression 6 to 18 months following discharge. Detriment to quality of life has been demonstrated to persist beyond two years post-injury and include PTSD, depression, loss of work, and repeated hospitalisation.

These results remind us of the interplay between clinical and sociopsychological mechanisms that underpin the efforts and the covenant of our health system. It is self-evident that survival to discharge

is a prerequisite for a favourable patient-centred outcome and that accurate and prompt intervention in major trauma maximises the potential for this. We are right to focus on these interventions if we are to give patients the best chance of recovery to a status that is meaningfully positive for them. However, critical care is not a zero-sum game, and while research and clinical interventions are—often appropriately—concentrated on early care it is imperative that robust, longitudinal attention is maintained throughout hospitalisation and extending beyond discharge to target outcomes less binary and reductive.

There remains a paucity of evidence aimed at studying nuanced long-term quality-of-life outcome data in major trauma and a need for a common language in their conveyance. The exclusion of this aspect of care from the 2007 NCEPOD review and its minimal reference in NHS Best Practice Tariffs, for example, seems at odds with our acknowledgement that they represent the fundamental goals in the care of patients subject to profound psychophysiological perturbations. Closely analysing these data may obligate us to contend that much remains to be done in this field, but it also allows us the best opportunity to formulate a coordinated approach to restore that which injury has distorted.

## Clinical Trials

For pragmatic reasons in a complex and heterogeneous group, rightly so trials have focused on short-term (hours to days or weeks) outcomes in critical care because these are the windows in which our biological interventions enmesh with pathophysiology. Although the length of ventilation or MAP itself may be a binary outcome of little pertinence to patients themselves, they are piquant with associated values like survival, degree of dependency, and mobility, and to an extent, it is foreseeable that levels of inflammation and infection have tendrils of impact on the neuronal biochemistry and internal

architecture that causes ongoing skeletal and nervous system dysfunction.

We also have a moral obligation to produce trials that are statistically powered for the results they seek, find the answer out most rapidly to bring improvements to a greater number of people, and do the least harm. Therefore, we will continue to see trials of vasopressor vs mortality or length of stay rather than cognitive performance or degree of dependency. However, there is no reason that we cannot generate a hypothesis using these latter values as secondary endpoints. For example, the working memory deficit is profound in post-intensive care syndrome and striking on the day in-clinic – and noradrenaline alone is known to affect its small, spiral conduit in the hippocampus. Meanwhile, stress, inflammation, cortisol, and sedative drugs will also, of course, play their part.

There is also no reason we cannot ask patients – the stakeholders themselves – what matters and to endorse these in real time on our units, amongst our distilled catecholamines and heparin-dusted pipes. A laudable study by Scheunemann et al. (2020) identified 12 core priorities for survivors of intensive care: feeling safe, being comfortable, engaging in mobility, participating in self-care, asserting personhood, connecting with people, ensuring family well-being, going home, restoring psychological health, restoring physical health, resuming previous roles and routines, and seeking new life experiences. Many of these reported outcomes, from interviews conducted in patients' homes

across the U.K., are not purely medicinal. It is impossible to attend a follow-up clinic and not find yourself gently murmuring to your draped or packaged-for-transfer patients.

## Intensive care impacts more than the patient, with ripple effects for their families, employers and wider societies

In the U.K., [NICE guidance](#) now has intensive care follow-up (for a certain severity) as a standard of care – ideally multi-disciplinary. Since follow-up has been a relatively recent innovation, protocols for RCTs on their utility in reducing morbidity and improving QoL are being published, but we have not received them as yet. A small study by Kowalkowski et al. (2022) looking at high-risk sepsis patients in the first month after discharge did show a reduction in 12-month hospital readmission but had not chosen to measure patient-centred outcomes.

A small Dutch study demonstrated that survivors with resultant psychopathology such as PTSD are in need of discharge information and would be willing to use a virtual reality module (Vlake et al. 2020). Despite efforts, a well-designed and multi-faceted nurse-led intervention, including a therapeutic ICU environment, stress support sessions, and identification of 'high-risk' patients, was not significantly superior for

prevention or poor psychological outcome at six months (Wade et al. 2019).

However, ongoing trials are designed to capture further data and test different interventions. Furthermore, as we begin to identify mechanisms behind other disorders of neuronal dysfunction, such as critical care associated neuro/myopathy or biological therapies for sepsis-associated encephalopathy (Krzyzaniak et al. 2023) we may begin to see therapies emerge for the cognitive pathology of post-intensive care syndrome.

## Conclusion

Interest and data serving long-term outcomes from intensive care are conspicuously sparse, and few specialties would tolerate such poor one-year outcomes. Intensive care also impacts more than the patient, with ripple effects for their families, employers and wider societies. Patient-centred outcomes will evoke greater humanity in their carers and further realise the success of an expensive and resource-intensive critical care admission, and patient-centred outcomes also reiterate the need for clinical therapies targeting the biological circuitry of our big hitting syndromes – ARDS, sepsis, delirium, renal failure – recognising they persist beyond the veil of discharge.

## Conflict of Interest

None.

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