

"Should ICU clinicians follow patients after ICU discharge?"

Joel Meyer, Stephen Brett and Carl Waldmann.

The trajectory of recovery from critical illness is often portrayed as a continuum. At one extremity lies an unstable patient dependent on life-sustaining treatments in the intensive care unit. At the other extremity stands an independent community-dwelling individual with restored personal, social and cultural wellbeing. A progressive transition from illness to recovery reflected by gradual de-intensification of healthcare occurs over many weeks to months.

This notion of a continuous arc of recovery is reflected poorly in the design of modern healthcare systems. Patients with similar care needs tend to be co-located for operational and economic reasons. This creates arbitrary institutional and professional boundaries which transect the care pathway. Transitions between intensive care, high dependency, ward and home are often fragmented, leading to loss of information, omissions in treatment and poor patient and family experience (Reference 1,2) .

The challenge of addressing fragmented care after ICU is epitomised at the crucial point of discharge home from hospital. Hospital clinicians perceive the moment of discharge home as a long anticipated goal marking near completion of clinical recovery. This fallacious mind-set is perpetuated during the hospital stay, generating unrealistic expectations of patients and caregivers about life at home. Passive transfer of clinical responsibility occurs via a written discharge document. As the notional separation between ICU and present day widens, so providers' familiarity with ICU-related interventions (and their complications) diminishes (Reference 3). This impacts on medication management, follow up investigations, specialist review and prompt referral to rehabilitation services.

For many ICU survivors release from hospital marks the start of an arduous struggle. Persistent physical, psychological and cognitive deficits arising from critical illness are highly prevalent (Reference 4). Patients and families lack understanding and context of their critical illness; resources to assist with life at home; and information about what recovery can be expected to involve (Reference 5). Pre-existing conditions may have been undertreated before admission or may interact to compound the complexity of care and deepen unmet need.

Another reality is that many patients will not make a full recovery following their critical illness. However deficits that cannot be reversed ought still to be identified, explained, reconciled. Resources can then be directed to adjusting to and coping with diminished quality of life after critical illness. This requires a patient- and family-centred approach extending beyond ICU and into the adaptive phase of recovery, enabling individuals to accomplish what matters most to them on a personal, social and economic level.

What is the relevance of post critical care follow-up services in this challenging landscape?

The last 20 years represent a dynamic period of multidisciplinary engagement with critical care survivors, moving beyond matters of life and death, and discovering the extent of their previously overlooked morbidity. The most prevalent service model for delivering follow-up is the outpatient clinic. To our knowledge the only conventionally designed trial of the post-ICU "clinic" concept is the PRaCTICaL study. In this well conducted study it was not possible to identify either a patient-centred

or health economic benefit. However, only one- possibly limited- clinic model was tested; arguably, the quantitative outcome measures may have been insensitive to change.

More recently we have learned how challenging demonstrating change can be (Reference 6). Of interest, the PIX study of a targeted exercise programme failed to shift a physiological outcome measure, yet a parallel qualitative evaluation demonstrated clear value for those in the intervention arm; patients felt more motivated, engaged and supported (Reference 7). This disparity between quantitative and qualitative findings is echoed in the RECOVER study that tested a greater level of rehabilitation support *within* hospital; the quantitative analysis failed to identify a measurable change, but the parallel qualitative analysis showed benefits (Reference 8).

Fundamental hurdles including heterogeneity of case-mix, lack of blinding, difficulty measuring the dose or magic bullet of a complex intervention, and incomplete knowledge about the outcome measures of interest may hamper comparative effectiveness trials in this field. Yet it is widely accepted and intuitive that follow-up activity is an effective intervention. The majority, 88%, of UK ICU clinicians surveyed on this topic cited financial constraints as the main barrier to ICU follow up whereas only 24% cited lack of current evidence for benefit and only 12% cited lack of clinical need (Reference 9) This implies a determination by frontline critical care staff to deliver follow up services in spite of the recognised barriers. The failure to demonstrate change in predominantly single intervention studies emphasises the need to develop and evaluate future projects as *complex interventions*: the RECOVER investigators adopted such an approach, although they were ultimately unable to show a benefit on their primary outcome measure (Reference 10).

Post ICU follow up services and associated programmes to enhance post ICU health are increasingly prevalent in the UK and globally. As of September 2017 the UK's National Institute for Health and Care Excellence (NICE) recommends healthcare commissioners ensure services they fund assess and provide a rehabilitation plan for survivors of critical illness (Reference 11):-

"Commissioners (clinical commissioning groups) ensure that they commission services that follow up adults who were in critical care for more than 4 days and at risk of morbidity with a review 2 to 3 months after discharge from critical care. They also ensure that services accept and reassess all adults who have had a critical care stay if they self-refer at any time after discharge."

Emerging concepts in recovery and rehabilitation are casting doubt on the relevance of a one-size-fits-all approach to follow-up (Reference 12). Recent observational data highlight the interaction between pre-existing conditions and post critical illness health trajectories (Reference 13). Tailored interventions may be needed for distinct post-critical illness subtypes (Reference 14). Mind and body 'cross-training' could provide a mechanism for the observation that cognitive rehabilitation can positively impact physical outcomes, and vice-versa. It is postulated that post traumatic growth may have a protective role in long term outcomes after life changing illness to be harnessed in the post critical care setting (Reference 15). Personal characteristics such as resilience, coping, and acceptance are relevant to health-related quality of life and may be modifiable through post ICU interventions (Reference 16).

The US Society of Critical Care Medicine Thrive Post ICU Collaborative was convened in 2017 to foster an international network of hospitals focussed on exploring diverse models of follow up. One such model is the innovative In:SPIRE (Intensive Care Recovery: Supporting and Promoting Independence and Return to Employment) project evaluating a 5-week post-ICU rehabilitation intervention in several centres in Scotland (Reference 17). Candidate follow up models tend to be

intensive care practitioner-delivered and patient co-designed clinics straddling traditional healthcare boundaries. Arguably these will be the attributes necessary to achieve patient-centred, cost-effective and integrated ICU follow up care which improves long term outcomes and successfully mirrors the continuum of recovery from critical illness.

Idea for a table/figure... for discussion/review

Follow up after ICU discharge has benefits for...						
The patient	The family	The ICU staff	The organisation /provider	The GP	The economy/public health	Research
Safety netting & coordination of ongoing care...address omissions in care/FU (Follow-Up)/meds Provide information/knowledge Contextualisation of life event Improve HRQOL (Health Related Quality of Life) Signpost to social and welfare benefits	Provide understanding and information Signpost to resources and support Expression of gratitude & emotional link to the unit	Realignment of purpose Contextualisation of daily efforts Reduce burnout/disillusionment Learn improve humanise care	Achieve NICE 83 and quality standard and GPICS (Guidelines for the provision of Intensive Care services) recommendations Improve pt and family experience Quality agenda Patient & family centred care	Improve ability to provide post ICU care through info/support	Reduced reattendance/readmission to hospital and use of emergency services More return to independence More return to work/gainful employment Reduce carer burden	Provides an environment in which to study survivorship/outcomes and recruit to studies

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