

Survivors of critical illness:

victims of our success?

*'For many patients the recovery after critical illness is relatively straightforward and it is important not to lose sight of this. What is clear is that tens of thousands of patients leave critical care to go home each year, and it is likely that poor-quality recovery represents a substantial problem. Given the individual impact on patients and ripple effects on families and society in general, poor-quality rehabilitation and impaired recovery from severe illness should be regarded as a major public health issue.'*¹

From its origins in Copenhagen during the poliomyelitis epidemic of 1952, the critical care unit has grown into a facility central to modern hospital medicine. Changes in medical practice and public expectation are placing increasing demands on critical care services. The Intensive Care National Audit & Research Centre recorded 96 810 admissions from April 2009 to March 2010 to 188 critical care units in England, Wales, and Northern Ireland, of whom 83.1% were discharged alive from critical care and 74.8% from hospital.²

Most patients admitted to critical care stay short periods of time and make complete and uncomplicated recoveries. However, follow-up of critical care survivors and caregivers has consistently shown that many report physical and psychological problems affecting quality-of-life, sometimes years after the admitting insult.³

These long-term effects were often overlooked by all but a few enthusiastic researchers.⁴ In 2009, the National Institute for Health and Clinical Excellence (NICE) published the clinical guideline *Rehabilitation after Critical Illness*.¹ It has provided a focus for changing clinical services in the UK. While changes have concentrated on care provided by critical care units, it is clear that for many patients and caregivers discharge from critical care marks the start of an uncertain journey. Primary care teams are likely to be involved in diagnosis and ongoing management of such patients.

HOW DOES PROLONGED CRITICAL ILLNESS AFFECT PATIENTS AND CAREGIVERS?

Patients entering critical care have significant organ failures, often on the

background of pre-existing organ dysfunction and comorbidities. Given that critical care and hospital admission can be for many months, it is not surprising that recovery will be protracted. In a recent essay describing her personal experience of recovery after critical illness Cheryl Misak, Professor of Philosophy at the University of Toronto, said 'It is hard to convey just how debilitated one is after an insult of ICU magnitude.'⁵

Respiratory failure and mechanical ventilation has defined critical care, particularly in the UK for many years. Even in acute respiratory distress syndrome the recovery of lung function in previously healthy survivors measured with pulmonary function tests is usually good. However, physical exercise capacity is significantly reduced compared with predicted values; the main reason given being muscle weakness and fatigue.³

'ICU-acquired weakness' is a recently coined term that encompasses disuse atrophy, loss of muscle mass, and a specific polyneuropathy recognised from neurophysiological testing. It begins early during critical illness, its incidence depends on the population studied and the tools used for detection, and it can have profound consequences on the critical care unit and beyond.³

Psychological sequelae after critical illness are common, and include anxiety, depression, sexual dysfunction, and post-traumatic stress disorder (PTSD).^{3,6} Much of this can be linked back to critical care, with sedation, delusional memory, poor sleep, hallucinations, and the critical care environment all contributing to problems.³ While these often settle with time and explanation by critical care staff, some will require specialist input from psychology colleagues. In addition long-term neurocognitive effects with deficits in memory, attention, and executive functioning are reliably reported.³ These problems may first manifest after hospital discharge and primary care teams will be

the first port of call for patients and carers seeking help.

The adverse effects of critical care on caregivers can be profound and long lasting. Relatives often feel confused and scared, living day-by-day, unable to plan ahead. With improvement in health come mixed emotions of joy, fear of deterioration, and uncertainty about the future. Informal caregivers of critical illness survivors have increased and persistent risks of depression, PTSD, lifestyle disruption and reduction in employment with financial consequences.⁷

CAN THESE CONSEQUENCES BE REDUCED AND HOW?

Critical care providers have begun to implement interventions on the critical care unit and beyond which may reduce the highlighted problems. These include optimal sedation and weaning practices, early mobilisation strategies on critical care, patient diaries, self-help rehabilitation manuals for home, and follow-up services.⁸⁻¹¹ Provision of follow-up services has been limited, with funding being the most commonly stated reason for this.¹¹ Many critical care units offer some form of service with dedicated individuals leading the service and available as a resource for primary care teams. While valued by patients, the structure and demonstrable benefits of such services remains debated.^{12,13}

DOES THE NICE GUIDELINE MATTER FOR PRIMARY CARE TEAMS?

NICE Clinical Guideline 83 makes recommendations about many aspects of rehabilitation during and after critical illness.¹ Particularly relevant to primary care teams is that all patients who required inpatient rehabilitation and their caregivers should have a functional assessment performed before hospital discharge. This should include physical and non-physical dimensions, assessment of the impact on activities of daily living, and agreement on

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future goals. Ongoing care, including referrals and documentation should be in place before discharge. Information should be given to patients and carers about recovery, expected improvement and progress, driving, return to work, housing and benefits, managing activities of daily living, local support groups, and hospital follow-up. This information should be made available to the primary care services that provide the day-to-day medical care.

In addition, NICE Clinical Guideline 83 recommends that those with rehabilitation needs are seen 2–3 months after critical care discharge for reassessment. Referral to appropriate rehabilitation services and specialist services should then be implemented if needed.¹ Disease specific rehabilitation has shown benefit in other situations such as pulmonary rehabilitation for chronic obstructive pulmonary disease.¹⁴ Unfortunately, at the moment such programmes do not exist for critical care survivors and options are often limited to generic referral to community physiotherapy or asking that patients are added on goodwill to existing pulmonary or cardiac rehabilitation programmes.

CONCLUSIONS

Critical care may not be a benign process, survivors of critical illness and caregivers are not simply grateful for survival, and their lives may be affected longer term by their experiences. Many patients will leave hospital with continuing physical and psychological care needs. Some may

develop problems after discharge and present to primary care services. GPs faced with such patients should be aware of the consequences of critical illness and not feel they have to cope in isolation. Some problems can be easily dealt with in primary care or through specific specialty referral. Other problems will be more difficult; national guidelines exist to support care and local critical care units may have a clinician leading post critical care services who can be accessed for advice. New evidence about the problems discussed and potential therapies will emerge from studies over the next few years; however, delivering novel services at a time of economic austerity will present many challenges.

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REFERENCES

1. National Institute for Health and Clinical Excellence. *Rehabilitation after critical illness*. NICE clinical guideline 83. London: NICE, 2009. <http://www.nice.org.uk/CG83> [accessed 26 Oct 2011].
2. Intensive Care National Audit and Research Centre. *CMP case mix and outcome summary statistics*. ICNARC, 2011. <https://www.icnarc.org/documents/Summary%20statistics%20rebranded.pdf> [accessed 26 Oct 2011].
3. Desai SV, Law TJ, Needham DM. Long-term complications of critical care. *Crit Care Med* 2011; **39(2)**: 371–379.
4. Griffiths RD, Jones C. Seven lessons from 20 years of follow-up of intensive care unit survivors. *Curr Opin Crit Care* 2007; **13(5)**: 508–513.
5. Misak CJ. ICU-acquired weakness: obstacles and interventions for rehabilitation. *Am J Respir Crit Care Med* 2011; **183(7)**: 845–846.
6. Griffiths J, Waldmann C, Quinlan J. Sexual dysfunction in intensive care survivors. *Br J Hosp Med (Lond)* 2007; **68(9)**: 470–473.
7. Van Pelt DC, Milbrandt EB, Qin L, et al. Informal caregiver burden among survivors of prolonged mechanical ventilation. *Am J Respir Crit Care Med* 2007; **175(2)**: 167–73.
8. Needham DM. Mobilizing patients in the intensive care unit: improving neuromuscular weakness and physical function. *JAMA* 2008; **300(14)**: 1685–1690.
9. Jones C, Bäckman C, Capuzzo M, et al. Intensive care diaries reduce new onset post traumatic stress disorder following critical illness: a randomised controlled trial. *Crit Care* 2010; **14(5)**: R168.
10. Jones C, Skirrow P, Griffiths RD, et al. Rehabilitation after critical illness: A randomized controlled trial. *Crit Care Med* 2003; **31(10)**: 2456–2461.
11. Griffiths JA, Barber VS, Cuthbertson BH, Young JD. A national survey of intensive care follow-up clinics. *Anaesthesia* 2006; **61(10)**: 950–955.
12. Prinjha S, Field K, Rowan K. What patients think about ICU follow-up services: a qualitative study. *Crit Care* 2009; **13(2)**: R46.
13. Cuthbertson BH, Rattray J, Campbell MK, et al. The PRaCTICaL study of nurse led, intensive care follow-up programmes for improving long term outcomes from critical illness: a pragmatic randomised controlled trial. *BMJ* 2009; **339**: b3723.
14. Nici L, Donner C, Wouters E, et al. American Thoracic Society/European Respiratory Society Statement on Pulmonary Rehabilitation. *Am J Respir Crit Care Med* 2006; **173(12)**: 1390–1413.