
ICU Volume 11 - Issue 3 - Autumn 2011 - Cover Story

Improving Long-Term Recovery after Critical Illness in the UK

Background

Critical Illness

Critical illness is any form of illness that represents an immediate threat to life. The major purpose of Intensive Care Units (ICUs) is to treat patients with potentially reversible forms of critical illness. Until recently, the major focus in ICU research has been on survival, usually short-term survival, and with modern day ICU treatment around 80% of critically ill patients survive to hospital discharge. However, attention is now moving from short-term survival to long-term outcomes and the process of long-term recovery after critical illness. Long-term recovery comprises physical performance, psychological function, and quality of life and Health Related Quality of Life (HRQoL), with the latter attempting to measure the overlap between health status and overall quality of life.

Critical Illness - A Growing and Important Public Health Problem?

Over 100,000 patients are admitted to ICUs in the United Kingdom (UK) per year. Of these over 40,000 are dead within one year of ICU admission (Cuthbertson et al. 2005). Over the five years after an ICU admission there is an excess risk of death when compared to an age and sex matched population (Wright et al. 2003). In the USA, six million individuals (2% of the population) are admitted to an ICU each year at a cost that exceeds 0.5% of Gross Domestic Product (over 100 billion US Dollars) (Halpern et al. 2004; Angus 2007). In the UK, the long-term outcome of patients that have experienced ICU treatment has been identified as a priority area by the Department of Health, acknowledged by the recent commissioning of a NICE guideline on the rehabilitation of survivors of critical illness (National Institute of Clinical Excellence, 2009). Long-term survival after critical illness - What is known and what is not known? The pattern, as well as determinants, of long-term survival following critical illness is now well described (Williams et al. 2008). Survival is worse in the first 6 to 12 months after discharge from hospital but, compared with age-, gender-, and era-matched members of the general population, survivors of critical illness have worse survival at all time points up to 15 years following ICU admission. In contrast to survival, much less is known about the pattern and determinants of long-term recovery, but a few conclusions are consistent across existing studies. During post-discharge follow-up survivors have a markedly lower HRQoL than an appropriately matched general population. Over-time, HRQoL tends to gradually improve although it generally remains lower than the matched general population (Dowdy et al. 2005). There is a definite occurrence of PTSD after critical illness though the reported range of incidence is wide (5 to 64%) (Griffiths et al. 2007). Clinically significant depression appears to be common though the reported incidence is also wide (8 to 61%) (Davydow et al. 2009). Age, pre-existing co-morbidities, severity of illness, and pre-existing poor health status and HRQoL have all been reported to contribute to poor long-term outcomes (Williams et al. 2008). However, although existing research has shown that ICU survivors experience an increased burden of psychological and physical illness following discharge, much of this literature is seriously flawed. The internal validity of existing studies is threatened by insufficient sample size to explore potentially relevant risk factors; insufficient duration of follow up to adequately describe recovery; selection bias related to high rates of loss to follow up, and inadequate adjustment, confounded by the fact that there are no studies that evaluate an adequate array of potential risk factors. Despite the recognition that a number of ICU patients experience significant problems with physical, psychological, and social functioning for some time after discharge there is little research into the economic impact of this morbidity on the patient and their immediate family. The only available evidence in the literature comes from two studies undertaken in the USA (Covinsky et al. 1994; Swoboda et al. 2002). These studies reported that 34% of seriously ill hospitalised patients required considerable care-giving assistance from a family member in the 12-months following hospital discharge, and in 20% of cases, a family member had to quit work or make another major life change to provide care for the patient.

The continuing problems of ill-health and economic difficulty has implications not just for patients, but imposes a continuing financial burden for the National Health Service (NHS) in terms of primary and secondary healthcare costs. It also imposes a potential burden on society and the benefit system that ultimately is responsible for the provision of financial support. However, there is a current lack of evidence in the literature on the economic impact of critical illness on survivors and its associations with overall HRQoL to inform this and future policy.

The ICON Study and i-Canuk Network

The primary aim of the collaborators associated with the ICON study and i-Canuk network is to further describe the longer-term HRQoL and personal economic costs in a multicentre population of survivors of treatment in UK ICUs, thereby significantly contributing to existing research in this field.

The ICON Study

ICON is a large multicentre study involving nearly 30 UK ICUs that has recruited almost 30,000 patients over five years. This study employs a 24-month follow up period with HRQoL measures administered at 3, 12 and 24 months after ICU discharge. The study protocol has been previously published (Griffiths et al. 2008). Phase one of the ICON study has recruited approximately 9,000 patients and trialled a questionnaire pack containing the Short Form-36 (SF-36) and the EuroQoL (EQ-5D), the Hospital Anxiety and Depression Scale (HADS) and the PTSD Civilian Checklist (PCL-C). A major aim of phase one of the ICON study was to demonstrate the efficacy of postal paper-based follow up methodology. Phase two followed up a further 18,000 patients after ICU discharge and randomised them to receive one of two questionnaire packs comprising of different combinations of the above named instruments. Phase one recruitment commenced in late 2006 and is now complete up to 24 months following ICU discharge. Phase two recruitment is in the process of being replaced by phase three. Phase three will apply even tighter follow up

© For personal and private use only. Reproduction must be permitted by the copyright holder. Email to copyright@mindbyte.eu.

protocols incorporating postal, telephone, fax, text/SMS and e-mail follow-up and an ever expanding patient tracking system.

The ICON study is now the world's largest registry of patients who have survived critical illness and will hopefully create a valuable UK database detailing the prevalence of physical and psychological morbidity experienced by patients as they recover from critical illness. Knowledge of the prevalence of physical and psychological morbidity in ICU survivors is important because research to generate models of causality, prognosis and treatment effects is dependent on accurate determination of prevalence. The results will also inform the economic modelling of the long-term burden of critical illness.

I-Canuk – The Intensive Care Aftercare Network

A national survey of post-ICU follow-up services in the UK was published in 2006 and demonstrated that at least 80 hospitals across the UK had developed post-ICU follow-up clinics in an attempt to improve outcomes after ICU discharge (Griffiths et al. 2006). This interest in the long-term outcome of survivors of ICU treatment in the UK fuelled the development of the i-Canuk network with the following mission statement:

- Promote the role of ICU follow-up services;
- Provide a forum for those involved or interested in ICU follow-up;
- Encourage investigation of the scientific base of physical, psychological and social consequences of critical illness;
- Produce educational and multimedia resources;
- Form partnerships between multi-professional care givers, industry, academia and patients and their families;
- Support evaluation of therapeutic options to improve outcomes following critical illness;
- Support the establishment of evidence-based standards and guidelines for follow up services, and
- Facilitate a national minimum dataset of post-ICU outcome measures.

A grant from the department of health was obtained in 2009 to fund the first collaborative research project of the i-Canuk network. Mirroring some of the methodology of the ICON study, i-Canuk has undertaken a pilot study of the long-term economic impact of critical illness and its association with the HRQoL of patients discharged from ICUs in the UK. This study employs similar instruments to the ICON study - EQ5D and SF36v2 - together with a novel economics questionnaire designed to detect changes in household income and the level of financial and personal dependence amongst the patient's family and the health services. The study is designed to further understanding of the economic impact of ICU admission and treatment on HRQoL, and the patient's family life and the health service usage. 840 patients have been recruited from 20 UK ICU sites over an 18-month period and the 24-month follow-up point was reached in April 2011 and analysis is underway. For both these studies, collaborative work with the UK Intensive Care National Audit and Research Centre (ICNARC) has allowed the patients' acute illness to be accurately characterised using a number of descriptors based on the Critical Care Minimum Dataset mandatory elements that are routinely captured by every ICU in England.

Lessons Learnt From the ICON Study and i-Canuk Study

To make long-term follow-up studies cost effective it is essential that study expenditure per patient remains as low as possible. The availability of a high quality national clinical audit organisation (ICNARC) has facilitated this; collaborative work with ICNARC has ensured that high quality patient descriptor data is married to the outcome data at relatively modest cost as systems and skills were already in place. Other considerations are the length of projected follow up, the number of patients to be recruited and the number of sites involved. As a direct consequence we have tried to continually develop newer, cheaper and more efficient methods of data gathering and processing. Whilst efficiency is certainly one important element to our work, the engendering of the good will of the staff involved at the recruiting sites is vital. Our group has invested significant time and effort in developing a computerised system that can handle and process the study data. Data enters the system in either electronic, paper based or manually inputted form. The format that the data is submitted to the study office in is at the discretion of the recruiting site in an attempt to minimise additional administrative load at the recruiting centre. The computer optically reads paper-based data and then all inputted data is subjected to a series of validity checks. The system identifies inadequate or missing data for each patient and posts letters to relevant ICUs asking for its completion. The studies inclusion and exclusion criteria are checked and valid patient data is retained. Over the course of the study an individual patient's mortality is continuously monitored via the office of national statistics. Additional automated checks are performed with each patient's GP directly before each point of contact from the study to try and prevent relative offence by trying to contact patients that have unfortunately died. When the system has confirmed that a patient remains alive, it generates a specific questionnaire and covering letter and then awaits the patients' reply, with further reminder prompting if required. Data returned to the study office is once again optically read, validated and then entered into the database.

Crucially, the system has the ability to score and calculate the various instruments using the data returned by each individual patient. This not only provides real time analysis, but also importantly enables on the spot identification of those patients reporting significant signs of underlying psychological disease. The system also has an inbuilt live consort diagram which tracks the patients from one stage of the study to another adding the capability to detect in real time, patients not conforming to the study protocol. On the spot analysis and consort diagram creation are all considered powerful and necessary tools to facilitate the smooth running of a study, which at any one point in time can be tracking several thousand active patients.

Future Directions

The results of phase one of the ICON study will hopefully be published at the end of this year, with the aim to publish the results of phase two shortly afterwards. The results of the i-Canuk pilot study of the economic impact of ICU treatment are also planned for publication and it is hoped that the pilot data can be used to refine the economics questionnaire and then apply it to a national UK or other European Union population. The addition of even longer follow-up periods, more complex case-mix data and more refined patient tracking, heralds an exciting new stage to HRQoL studies in ICU survivors. Rigorous, long-term follow-up observational data is essential to acquire the information necessary to plan and conduct future randomised controlled trials to evaluate emerging candidate interventions that aim to improve recovery after critical illness.

Published on : Thu, 15 Aug 2013