Experience from multidisciplinary follow-up on critically ill patients treated in an intensive care unit

Lise Fonsmark & Mette Rosendahl-Nielsen

ABSTRACT

INTRODUCTION: International literature describes that former intensive care unit (ICU) patients suffer considerable physical and neuropsychological complications. Systematic data on Danish ICU survivors are scarce as standardised follow-up after intensive care has yet to be described. This article describes and evaluates the knowledge gained from outpatient follow-up at a tertiary intensive care unit at Rigshospitalet, Copenhagen, during a three-year period.

METHODS: A total of 101 adult former ICU patients attended the outpatient clinic over a three-year period. Patients included were medical and surgical patients with a length of stay exceeding four days. Patients attended the clinic after discharge from hospital and for a minimum of two months from their discharge from the ICU. The patients were assessed for physical, neuropsychological and psychological problems and, if necessary, further treatment or rehabilitation was initiated.

RESULTS: Reduced physical ability was seen in 82%. A total of 89% suffered a substantial weight loss. 83.2% had signs indicating acute brain dysfunction during the ICU stay, and approximately half of the patients still had cognitive problems. A total of 66 interventions were initiated.

CONCLUSION: Our data confirmed that a large proportion of ICU survivors suffer considerable long-term physical and neuropsychological sequelae. Intensive care follow-up may contribute to address these specific problems and to initiate the needed interventions. Research is needed to determine whether specialised rehabilitation is required.

FUNDING: not relevant.

TRIAL REGISTRATION: not relevant.

For many years the primary effect of intensive care has been evaluated in terms of survival, but during the past 10-15 years there has been an increasing interest in the complications that survivors are facing. Studies have shown that former intensive care unit (ICU) patients often suffer considerable physical and neuropsychological complications resulting in need for specialised rehabilitation [1-7]. The complications associated with critical illness and intensive care therapy are now widely accepted, and a term has been coined, post-intensive care syndrome (PICS), covering the physical, cognitive and psychological complications [8, 9]. For further details on PICS, see **Table 1**. The syndrome frequently persists for months or even years and restricts activities of daily living, reduces quality of life and the ability to return to former employment [10-12].

The complications are predominantly related to the critical illness and ICU stay and only to a minor degree to the primary disease. This results in a need for rehabilitation that cannot necessarily be managed by the referring medical or surgical department [13].

This knowledge has resulted in establishment of various ICU outpatient follow-up programmes, but only few such programmes exist in Denmark.

On this basis, Intensive Care Unit 4131 at Rigshospitalet in 2010 decided to set up a multidisciplinary follow-up clinic to assess the physical and/or psychological impact of critical illness on former ICU patients and to offer guidance and treatment and to refer patients for further treatment as needed.

The aim of this paper was to describe and evaluate the knowledge gained from our three-year ICU outpatient follow-up.

METHODS

Setting

The data presented in this paper were generated from follow-up visits of former ICU patients in ICU 4131, Rigshospitalet in the period from 1 September 2010 to 31 August 2013. The department is a multidisciplinary 23-bed unit treating both medical and surgical patients, including patients with severe infections, trauma, burns, haematological diseases, liver transplants and need for extensive vascular surgery.

Included patients

All adult patients (> 18 years) with a length of stay (LOS) in ICU > 4 days and a LOS in hospital > 10 days were included in the follow-up programme, as patients admitted for a shorter period are usually less seriously ill and supposedly do not to need a follow-up visit. We only invited residents from The Capital Region of Denmark as we did not have funding allowing us to defray costs for patient transportation. Patients who did not speak Danish or had a pre-existing major psychiatric diagnosis, severe brain damaged or had dementia were excluded along with patients who were transferred for terminal care or treated primarily in other units.

ORIGINAL ARTICLE

Intensive Care Unit 4131, Rigshospitalet, Denmark

Dan Med J 2015;62(5):A5062

TABLE 1

Post-intensive care syndrome [8].

Complication	Description
Pulmonary	Impairment in spirometry, lung volumes and diffusion capacity
Neuromuscular	Includes critical illness, polyneuropathy and myopathy Disuse atrophy
Physical function	Impairment in activities and instrumental activities of daily living and 6-min walking distance
Psychiatric symptoms	Depression Post-traumatic stress disorder Anxiety
Cognitive	Impairments in memory, attention, executive function
Quality of life	Deficits most observed in physical domains

The outpatient visit

After discharge from hospital, the patients were contacted and invited for a follow-up consultation. Provided the patient accepted, an appointment was made in the outpatient clinic. At the same time an information pamphlet covering the most common problems after critical illness was sent to the patient along with a questionnaire to determine anxiety and depression (HADS). The patients were encouraged to bring along their closest relatives.

The visits took place at least two months after discharge from the ICU, and they lasted approximately 90 minutes. Apart from the patient and relatives, the nurse and doctor from the outpatient's clinic participated. The ICU medical history was discussed on the basis of the patient's and their relatives' experience of the stay, questions were answered and the course of the ICU stay was explained, if desired. In addition, the patient was assessed for existing physical, neuropsychological or psychological problems that require further treatment or rehabilitation based on a medical evaluation. If necessary, this was initiated either via direct referral or via the patient's general practitioner. The patient was also invited to visit the ICU's patient area.

Trial registration: not relevant.

RESULTS

A total of 304 patients fulfilled the inclusion criteria; out of these, 101 attended the Outpatient Clinic (**Figure 1**). Patient characteristics are shown in **Table 2**.

Physical complications

82.2% of the patients (83/101) stated that they still had limitations in their physical ability in terms of general physical fitness and muscular strength compared with their pre-ICU condition. Among the 83 patients, physical rehabilitation was initiated or continued after discharge from hospital for 68.7%. Whereas 48.2% of the patients still attended an active training programme, it was assessed that 84.3% of the patients with limited physical ability would benefit from further training.

Of the 49 patients who had been in employment before the ICU event, only 16 had returned to full or part-time work.

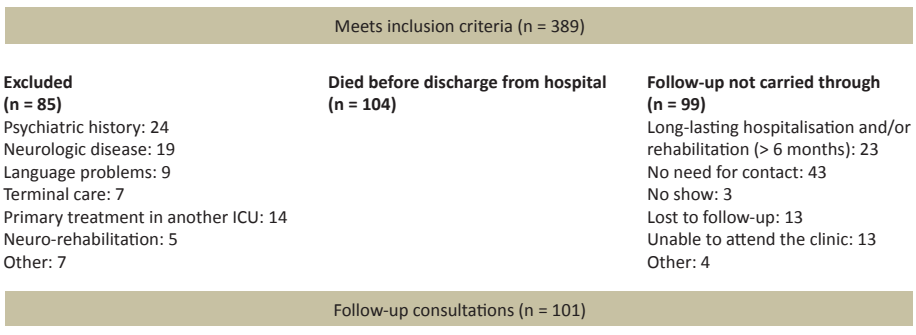
The majority of the patients (95%) underwent ventilator treatment during their ICU stay. The median ventilator time was five days (quartiles: 4-12.5). Ten of the patients had complications related to ventilation, seven had voice changes and three experienced constriction from the tracheotomy wound.

Most of the patients (89%) suffered a substantial loss of weight; a median of 10 kg (quartiles: 8-16). In all, 40% had experienced changes in taste, either that the food was tasteless or everything tasted wrong or metallic. Most of these symptoms faded over time, but 20% of the patients still had loss of appetite.

Neuropsychological complications

Less than half of the patients reported having factual

FIGURE 1



Flow diagram showing the reasons why most patients did not attend follow-up consultation. ICU = intensive care unit.

memories of the ICU stay, whereas 80% remembered delusions or hallucinations. According to the medical records, 64.3% of the patients were diagnosed with delirium during their ICU stay (although only a few were screened by The Confusion Assessment Method for the ICU CAM-ICU). Nineteen of the 28 patients *not* diagnosed with delirium still had clear memories of delusions. In all, 84 patients out of the 101 (83.2%) had signs indicating acute brain dysfunction during their ICU stay. The term acute brain dysfunction is used instead of delirium, since a systematic screening for delirium during the ICU stay was not performed, and no consistent diagnostic criteria were used to diagnose delirium. In the clinical practice, signs such as agitation, hallucinations and delusions were used for diagnosing acute brain dysfunction.

When patients attended the outpatient clinic, approximately half described recent cognitive problems including difficulty with concentration, reading/understanding and/or loss of memory.

Psychological complications

A total of 88 of the patients had completed the HADS questionnaire. 36% of the 88 tested positive for anxiety, whereas 29% tested positive for depression. The patients were not screened for post-traumatic stress disorder, but only two patients had on-going sleep disturbances, nightmares and flashbacks.

Interventions

Among the 101 patients visiting the outpatient clinic, 12 were instructed regarding further physical training, while nine received instructions concerning nutritional matters. Eight patients were referred to further physical rehabilitation, mostly via their general practitioner.

Two patients were referred to psychiatric treatment one of whom was hospitalised due to acute psychosis.

Six patients had problems related to the surgical procedure or disease that caused the original ICU admission and they were referred to the surgeon in question. Another six patients were in need of further follow-up regarding their medical disease and were referred to the medical department. Four patients with change in voice or hoarseness following intubation were referred to an otologist. One patient was referred for computed tomography of the cerebrum and neurosurgical treatment due to a chronic subdural haematoma.

A total of 12 patients were prescribed pain therapy, whereas seven needed other interventions such as referral to physiotherapy or occupational therapy, enterostomal therapy, radiology, biochemical control or minor adjustments in medication, **Table 3**.

TABLE 2

Patients characteristics.

Age, yrs, median (quartiles)	60 (49-66)
APACHE II score, median (quartiles)	23 (18-27)
LOS, intensive care, days, median (quartiles)	8.5 (5-22)
Males, n (%)	62 (61.4)
Ventilator treatment, n (%)	96 (95)
Ventilator days, median (quartiles)	5 (4-12.5)
Diagnosis, n (%)	
Ruptured abdominal-aortic aneurysm	16 (15.8)
Liver transplantation	9 (8.9)
Respiratory insufficiency	17 (16.8)
Burns	5 (5.0)
Necrotising fasciitis	15 (14.9)
Severe sepsis/septic shock	13 (12.9)
Trauma	5 (5.0)
Post-operative complications	8 (7.9)
Meningitis	7 (6.9)
Mixed	6 (5.9)

APACHE II = Acute Physiology and Chronic Health Evaluation II; LOS = length of stay.

TABLE 3

Interventions, advice and guidance.

	n/N (%)
Interventions	44/101 (43.6)
Referral to physical rehabilitation	8
Referral to general practitioner	13
Referral to psychiatrist (1 patient acutely hospitalised)	2
Referral to surgeon	6
Referral to medical physician	6
Referral to otologist	4
Referral to neurologist	2
Pain treatment initiated	12
Others	7
Advice and guidance	22/98 (22.4)
Advice and guidance on physical training	12
Dietary advice	9

DISCUSSION

Our data show that the problems following critical illness and ICU stay coined PICS, as described in the international literature, are also found in the Danish population, both in terms of physical and neuropsychological complications. As our data show, reduced physical ability is seen in 82% who suffer loss of total muscle mass, exhaustion and extreme fatigue. Early ambulation, physiotherapy and active training during the ICU stay has been shown to improve physical ability at discharge from the ICU and to reduce LOS and time on a ventilator [14-16]. Early mobilisation is facilitated by patients being awake and able to actively participate in their own care, why sedation should be kept at a minimum, as stated in the Danish national sedation strategy [17].

It is crucial that rehabilitation and physical training continue after transfer to a general ward and after discharge from hospital. Our data show that physical rehabilitation was only initiated and continued after discharge for two thirds of the patients who were describing reduced physical ability compared with their pre-ICU conditions. In some cases, rehabilitation was delayed for more than four weeks, possibly causing stagnation, slowing down recovery and reducing the patient's ability to return to work. In some cases, the missing or delayed rehabilitation was due to rehabilitation not being prescribed at the time of discharge from hospital. In other cases, the prescription was not received by the community health service. Furthermore, there seems to be a substantial variation in the number of rehabilitation programmes that are available at various local authorities. To improve the chance for full recovery in these debilitated patients, a strong effort should be made both intrahospitally and among the local authorities.

Nutritional deficiency is a major issue associated with the loss of total muscle mass and reduced physical ability. Almost all patients experienced a substantial loss of weight. The loss of appetite and changes in taste following critical illness, in combination with extreme fatigue and exhaustion, cause an insufficient food intake and further loss of weight after discharge from the ICU, or even after discharge from the hospital. There seems to be a need for identification of these cases and for intensified individual nutritional support, if necessary in collaboration with a dietician.

The rate of acute brain dysfunction/delirium was high in the study population. This, combined with the fact that many patients have little or no recall of real events during their ICU stay, causes concern as to the extent to which the patient can be involved in decision-making during his or her ICU stay, for example decisions concerning restrictions in therapy or participation in medical research.

Long-term or even permanent cognitive problems following critical illness are more frequently seen in patients with delirium during their ICU stay [18]. Therefore, the prevention, diagnosing and treatment of delirium appear to be urgent [19]. Currently, the understanding of how to minimise or avoid these complications is limited. Data gathered in the area of specialised neuro-rehabilitation are presumably valuable to patients with cognitive problems following critical illness, but this area is in need of investigation [19].

After discharge from hospital, most former ICU patients attend the outpatient medical or surgical clinic responsible for treatment of their underlying disease. During severe critical illness, the patient often develops multiple organ failure with subsequent problems that require further investigation and treatment, and these are not necessarily dealt with by the general ward's practitioners. Additionally, patients experience complications to treatment performed in the ICU, such as sequelae following intubation, that require further examination and treatment by other specialists. Finally, some of the problems following ICU stay are a consequence of the critical illness itself. In our population, 33% of the patients were referred to a second medical speciality, indicating that a co-ordinator, preferably in the hospital setting, would be useful for these patients to ensure co-ordination of any necessary further examinations, treatment and rehabilitation. Furthermore, our knowledge of the long-term consequences of critical illness and ICU stay calls for increased mindfulness and education of the health-care staff involved in the care of these patients [9].

The purpose of this study was to describe problems and complications experienced by former ICU patients. The main weakness of the study is that roughly half of the patients meeting the criteria for a follow-up visit did not attend the clinic for several reasons (Figure 1). A considerable share of these patients stated that they did not need a follow-up consultation. The reason for not attending the clinic was not evaluated systematically. Therefore, we cannot exclude that our study represents the number of complications only in a selected group of patients rather than describing the incidence of post-intensive care problems in general. However, according to the medical records, the patients were comparable with patients attending the clinic with regard to diagnosis, LOS in ICU (median nine versus 8.5 days) and APACHE II scores (median 23 versus 23). Patients not attending the clinic only differed slightly with regard to age (median 60 versus 54 years) and delirium during their ICU stay (59% versus 64.3%). We cannot exclude that patients not attending the follow-up clinic had experienced the same kind of problems, but had moved on or had even more severe problems, leading to physical difficulty or reluctance in attending.

CONCLUSION

Our data have confirmed that a large proportion of ICU survivors suffer considerable long-term physical and neuropsychological sequelae. Intensive care follow-up may contribute to address these specific problems and to initiate the needed interventions. Research is needed to determine whether specialised rehabilitation is required.

CORRESPONDENCE: *Lise Fonsmark,* ICU 4131, Rigshospitalet, Blegdamsvej 9, 2100 Copenhagen Ø, Denmark. E-mail lise.fonsmark@regionh.dk

ACCEPTED: 25 February 2015

CONFLICTS OF INTEREST: none. Disclosure forms provided by the authors are available with the full text of this article at www.danmedj.dk

ACKNOWLEDGEMENTS: *Lene Russel Løvbjerg*, Rigshospitalet, for proof-reading. *Kirsten Kofoed*, Rigshospitalet, for providing the secretarial services needed at the Outpatient Clinic.

LITERATURE

1. Rosendahl-Nielsen M. Moving on after critical illness and intensive care. A qualitative study on former mechanically ventilated patients' experiences. Aarhus: Aarhus University, Department of Public Health, Section for nursing, 2009.
2. Kancir CB, Fonsmark L. Physical and neuropsychological sequelae after intensive therapy. Ugeskr Læger 2007;169:697-9.
3. Jackson JC, Ely EW, Morey MC et al. Cognitive and physical rehabilitation of intensive care unit survivors: results of the RETURN randomized controlled pilot investigation. Crit Care Med 2012;40:1088-97.
4. Torgersen J, Hole JF, Kvåle R et al. Cognitive impairments after critical illness. Acta Anaesthesiol Scand 2011;55: 1044-51.
5. Wolters AE, Slooter AJC, van der Kooi AW et al. Cognitive impairment after intensive care unit admission: a systematic review. Intens Care Med 2013; 39:376-86.
6. Griffith R, Jones C. Intensive care aftercare. Elsevir: Butterworth-Edinburgh: Heinemann, 2003.
7. Herridge MS, Tansey CM, Matté A et al. Functional disability 5 years after acute respiratory distress syndrome. N Engl J Med 2011;364:1293-1304.
8. Desai SV, Law TJ, Needham DM. Long-term complications of critical care. Crit Care Med 2011;39:371-9.
9. Needham DM, Davidson J, Cohen H et al. Improving long-term outcomes after discharge from intensive care unit: report from a stakeholders' conference. Crit Care Med 2012;40:502-9.
10. Kress JP, Herridge MS. Medical and economic implications of physical disability of survivorship. Semin Respir Crit Care Med 2012;33:339-47.
11. Kress JP, Hall JB. ICU-acquired weakness and recovery from critical illness. N Engl J Med 2014;370:1626-35.
12. Hopkins RO, Girard TD. Medical and economic implications of cognitive and psychiatric disability of survivorship. Semin Respir Crit Care Med 2012;33:348-56.
13. Denehy L, Elliot D. Strategies for post ICU rehabilitation. Curr Opin Crit Care 2012;18:503-8.
14. Morris PE, Goad A, Thompson et al. Early intensive care unit mobility therapy in the treatment of acute respiratory failure. Crit Care Med 2008;36:2238-43.
15. Burtin C, Clerckx B, Robbeets C et al. Early exercise in critically ill patients enchances short-term functional recovery. Crit Care Med 2009;37:2499-2505.
16. Schweickert WD, Pohlman MC, Pohlman AS et al. Early physical and occupational therapy in mechanically ventilated, critically ill patients: a randomised trial. Lancet 2009;373:1874-83.
17. Hein L, Strøm T, Nibroe H, Bundgaard H et al. Sedation strategy – goal-directed treatment of discomfort in connection with critical illness. DASAIM 2010. www.dasaim.dk/wpcontent/uploads/2014/02/Sedationsstrategi_samlet.pdf (1 May 2014).
18. Pandharipande PP, Girard TD, Jackson JC et al. Long-term cognitive impairment after critical illness. N Engl J Med 2013;369:1306-16.
19. Wergin R, Modrykamien A. Cognitive impairment in ICU survivors: assessment and therapy. Cleve Clin J Med 2012;79:705-12.